

An Exploratory Study of Formal Support Factors and Quality  
of Life for Adults with Asperger's Syndrome

A Thesis Submitted to the College of Graduate  
Studies and Research in Partial Fulfillment of the  
Requirements for the Degree of Master's of Education in the  
Department of Educational Psychology and Special Education  
University of Saskatchewan  
Saskatoon

By

Brendan Newton

© Brendan Newton, November 2009. All rights reserved.

## PERMISSION TO USE

In presenting this thesis in partial fulfillment of the requirements for a Postgraduate degree from the University of Saskatchewan, I agree that the Libraries of this University may make it freely available for inspection. I further agree that permission for copying of this thesis in any manner, in whole or in part, for scholarly purposes may be granted by the professor or professors who supervised my thesis work or, in their absence, by the Head of the Department or the Dean of the College in which my thesis work was done. It is understood that any copying or publication or use of this thesis or parts thereof for financial gain shall not be allowed without my written permission. It is also understood that due recognition shall be given to me and to the University of Saskatchewan in any scholarly use which may be made of any material in my thesis.

Requests for permission to copy or to make other uses of materials in this thesis in whole or part should be addressed to:

Head of the Department of Educational Psychology and Special Education  
University of Saskatchewan  
Saskatoon, Saskatchewan S7N 0X1  
Canada

OR

Dean  
College of Graduate Studies and Research  
University of Saskatchewan  
107 Administration Place  
Saskatoon, Saskatchewan S7N 5A2  
Canada

## Abstract

Although the concept of quality of life (QOL) has become increasingly popular in the past few decades in a number of fields of research, few studies have specifically examined QOL for high-functioning individuals with autism spectrum disorders. Several studies have found that objectively measured outcomes for adults with high-functioning autism (HFA) and Asperger's syndrome (AS) tend to be poor in terms of employment, relationships, mental health, and independence. However, it has been recently suggested that in order to obtain a more accurate depiction of overall QOL, subjective impressions must be examined as well. Recent research has found that the most significant predictor variable of QOL for high-functioning individuals with autism spectrum disorders is the discrepancy between support needed and formal support provided. The current study examined 15 formal support variables and their relationships to subjective QOL scores on the WHOQOL-BREF, in 4 domains (physical health, psychological health, environment, and social relationships) as well as overall QOL. A total of 33 participants completed a questionnaire that included items designed to obtain information on demographics and formal support. Participants also completed the WHOQOL-BREF in order to obtain overall QOL scores along with QOL domain scores. Significant negative correlations were found between Environmental QOL scores and the accessing of a social worker as well as the accessing of social groups. Significant negative correlations were also found between Social QOL scores and the accessing of a psychiatrist and a single-item overall QOL score and the accessing of counselling or psychotherapy. All correlations between formal support factors and QOL scores showed lower QOL scores for those individuals who accessed the supports. The results of standard multiple regression analyses revealed a significant model that accounted for 49% of the

total variance in the amount of total supports accessed as well as two other significant models predicting Social QOL and Environmental QOL.

## Acknowledgements

First and foremost, I would like to thank my supervisor, Dr. Tim Claypool, who supported me throughout the entire process and encouraged me to persevere. His guidance and positive attitude were extremely reassuring. I would like to thank Dr. Laurie Hellsten, who was a member of my thesis committee. Dr. Hellsten's advice and support were invaluable in allowing me to successfully complete this thesis. I would also like to acknowledge Dr. Keith Walker, my external examiner for my thesis defense. Dr. Walker's recommendations helped to add clarity to my thesis and resulted in an overall improvement in my work.

I would like to thank Asperger's Manitoba Incorporated for allowing me to work with them on this project and assisting me throughout. Their organization provides support, advocacy, and education to individuals with Asperger's syndrome and their families. It was their organization who envisioned this project and I am privileged to have worked with them.

Finally, I would like to thank my wife, Mary, my mother, Elizabeth, my sister, Janine, my brother, Paul, my sister-in-law, Teresa, and my father-in-law and mother-in-law, Doug and Donna. Their encouragement and positivity throughout this process were what allowed me to succeed more than anything else.

## Dedication

I would like to dedicate my thesis to my wife, Mary. Her passion and dedication for working with individuals with autism spectrum disorders is what inspired me to take on this project. Her understanding, encouragement, and patience were what allowed me to complete it.

## Table of Contents

CHAPTER 1: INTRODUCTION.....	1
<i>Chapter Synopsis</i> .....	1
<i>Asperger's Syndrome and Quality of life</i> .....	1
<i>Background</i> .....	2
<i>Purpose of Proposed Research</i> .....	5
CHAPTER 2: LITERATURE REVIEW.....	7
<i>Chapter Synopsis</i> .....	7
<i>Historical Context</i> .....	7
<i>Autism Spectrum Disorders</i> .....	8
<i>Differential Diagnosis</i> .....	10
<i>Prevalence</i> .....	23
<i>Adult Outcomes</i> .....	23
<i>Quality of Life Research</i> .....	27
<i>Quality of Life Measurement</i> .....	31
<i>Support and Quality of Life</i> .....	33

<i>Purpose of Current Study</i> .....	34
<i>Conclusion</i> .....	35
 CHAPTER 3: METHODOLOGY.....	37
<i>Chapter Synopsis</i> .....	37
<i>Sample</i> .....	37
<i>Procedure</i> .....	38
<i>Measures</i> .....	40
<i>Questionnaire</i> .....	40
<i>WHOQOL-BREF Survey</i> .....	42
<i>Statistical Analysis</i> .....	45
<i>Conclusion</i> .....	46
 CHAPTER 4: RESULTS.....	47
<i>Chapter Synopsis</i> .....	47
<i>Demographic Information</i> .....	47
<i>Descriptive Statistics</i> .....	48



<i>Diagnoses</i> .....	48
<i>Living Arrangements</i> .....	49
<i>Education and Employment</i> .....	50
<i>Finances</i> .....	51
<i>Daily Living</i> .....	52
<i>Social Relationships</i> .....	53
<i>Incidents with the Law</i> .....	54
<i>Physical Health Concerns</i> .....	54
<i>Mental Health Concerns (Anxiety and Depression)</i> .....	55
<i>The Need for Support</i> .....	56
<i>Formal Supports</i> .....	56
<i>Statistical Analysis</i> .....	60
<i>Data Screening</i> .....	60
<i>Missing Data</i> .....	61
<i>Distributions</i> .....	62
<i>Correlations</i> .....	64
<i>Regression Analyses</i> .....	66
<i>Conclusion</i> .....	68

CHAPTER 5: DISCUSSION.....	69
<i>Chapter Synopsis</i> .....	69
<i>Findings</i> .....	69
<i>Limitations</i> .....	79
<i>Future Research</i> .....	83
<i>Conclusion</i> .....	85
References.....	87
Appendix A: Questionnaire.....	99
Appendix B: WHOQOL-BREF survey.....	107
Appendix C: Application to the Behavioural Research Ethics Board.....	115
Appendix D: Ethics Approval.....	126
Appendix E: Recruitment Email.....	127
Appendix F: Electronic Consent Form.....	129

## List of Tables

Table 1 Comorbid Diagnoses.....	49
Table 2 Number of Participants Indicating Needed Assistance for Activities.....	52
Table 3 Number of Participants Agreeing or Disagreeing with Support Statements.....	57
Table 4 Number of Participants Accessing Different Types of Formal Support.....	58
Table 5 Number of Participants Indicating They Would Benefit From Supports.....	59
Table 6 Skewness and Kurtosis Values for Distributions.....	63
Table 7 Multiple Correlation Values for Three Regression Models.....	67

## List of Abbreviations

QOL: Quality of Life

AS: Asperger's Syndrome

HFA: High-Functioning Autism

PDD: Pervasive Developmental Disorder

## CHAPTER1: INTRODUCTION

### *Chapter Synopsis*

The purpose of this first chapter is to provide a brief overview of the research conducted, to date, in the area of Asperger's syndrome (AS) and quality of life (QOL) and to explain the purposes of the current research study. The chapter begins with a short introduction to the topic of QOL as it pertains to autism spectrum disorders as well as some of the limitations and shortcomings of the previous research in this area. The chapter continues with a section describing the first documented cases of AS, the increasing interest in the disorder over the past few decades, the controversy over the legitimacy of AS as a distinct Pervasive Developmental Disorder (PDD) subtype, and the current epidemiological data related to the disorder. Finally the chapter ends with a short explanation of the current trends in the research, an argument in favour of the necessity of a different approach, and the purpose of the current research study. This chapter is followed by a thorough literature review in which the reader is provided with a more comprehensive summary of the research that has been conducted in the area of QOL and autism spectrum disorders. The Literature Review chapter is followed by a Methodology chapter that describes the research methods that were employed in this study. Following this a Results chapter has been included to give an overview of the findings of this study. The final Discussion chapter focuses on interpreting the results of the study and considering the implications of the findings.

### *Asperger's Syndrome and Quality of Life*

Although the concept of QOL has become increasingly popular in the past few decades in a number of fields of research, few studies have specifically examined QOL for high-functioning individuals with autism spectrum disorders. Several studies have found that objectively measured

outcomes for adults with high-functioning autism (HFA) and AS tend to be poor in terms of employment, relationships, mental health, and independence (Howlin, 2000; Engstrom, Ekstrom, and Emilsson, 2003; Howlin, Goode, Hutton, & Rutter, 2004; Hurlburt & Chalmers, 2004; Wing, 1981; Gillberg, 1985; Ghaziuddin, Weidmer-Mikhail, & Ghaziuddin, 1998). However, the research regarding subjective impressions of QOL for these individuals is limited considering the fact that current research in QOL measurement has suggested the need for subjective measures in determining overall QOL (Schalock, 2004). Moreover, several studies (Engstrom, I., Ekstrom, L. & Emilsson, B., 2003; Howlin, P., 2000; Mawhood, L. & Howlin, P., 1999; Renty, J. & Roeyers, H., 2006) that have attempted to examine QOL have combined HFA and AS participants as one group due to a lack of consensus in the field over the legitimacy of AS as a condition distinct from all other PDDs. However, regardless of whether AS and HFA actually represent two distinct disorders on the higher-functioning end of the autism spectrum, the fact remains that due to their verbal and cognitive abilities, their tendency to be diagnosed much later (Howlin and Asgharian, 1999), and differences in support and funding (Missiuna, Pollock, Caltagirone, Maggioira, & Zwaigenbaum, 2003; Tantum, 2003; Schopler, 1998; Klin and Volkmar, 2000; Autism Ontario, 2008), these individuals will likely have much different life experiences than those with a diagnosis of autism. Thus, it is imperative for their well-being that QOL studies of individuals with autism spectrum disorders treat AS as a unique subgroup. The purpose of the proposed study is to examine whether any specific formal support factors relate to the subjective impressions of QOL in four specific areas.

### *Background*

In 1944 an Austrian physician by the name of Hans Asperger described a group of children with whom he had been working. Asperger noted that these children shared a unique set

of characteristics, including social impairment, poor motor coordination, proper speech and grammar, poor intonation and prosody, and average to above average intelligence. However, although Asperger's observations were thoroughly documented, it was not until 1981 when Lorna Wing reintroduced Asperger's work to the western world, that AS was given recognition. Since that time AS has increasingly become a focus for research and several studies have been conducted to investigate whether there are underlying differences between AS and other PDDs (Schopler, Mesibov, & Kunc, 1998).

Like AS, the term HFA has also been used regularly in the literature to categorize individuals who qualify for a diagnosis of autism but have average to above average cognitive abilities. However, at the present time, only AS has been given official status in the Diagnostic and Statistical Manual of Mental Disorders (DSM) (American Psychiatric Association & DSM-IV-TR, 2000) and the International Classification of Diseases (ICD-10) (World Health Organization, 1992). Thus, the term HFA is currently only an unofficial label used to denote the cognitive abilities of individuals who have a diagnosis of autism. However, due to the difficulties finding legitimate differences between individuals with HFA and AS (Howlin, 2003; Wing, 1998; Szatmari, 1998), several researchers have concluded that these two conditions may simply be different labels for the same disorder (Schopler & Mesibov, 1998).

Currently, both the DSM and ICD-10 indicate that it is the presence or absence of a language delay during development that separates AS from Autistic Disorder. That is, if a significant language delay was present during development a diagnosis of autism must follow. If no language delay is documented then AS is the most appropriate diagnosis. However, the necessity of normal language development for a diagnosis of AS has been challenged (Wing, 1981; Tantam, 1988; Gillberg, 1989, Attwood, 2004) and several researchers have actually found

that the presence of a language delay in development does not significantly discriminate between AS and HFA after the first few years of life. (Howlin, 2003; Gilchrist, Green, Cox, Burton, Rutter, and Le Couteur, 2001; Eisenmajer et al., 1998; Mayes and Calhoun, 2001). While several studies have found differences between these two populations at later stages (Klin, Volkmar, Sparrow, Cicchetti, and Rourke, 1995; Ghaziuddin and Mountain-Kimchi; 2004; Ehlers et al., 1997; Miller & Ozonoff, 2000; Szatmari, Bryson, Boyle, Streiner, and Duku, 2003; Ozonoff, Rogers and Pennington, 1991; Lotspeich et al., 2004), the legitimacy of the results obtained in some studies have been questioned on the basis that the selection criteria used were too closely related to the dependent variables, resulting in a degree of circularity (Wing, 1998; Szatmari, 1998; . Klin 1994 as cited in Klin et al., 1995) Nevertheless, AS continues to be officially recognized as a separate PDD and as a result many individuals have been, and continue to be, provided with this diagnosis. Furthermore, although there is a considerable lack of consensus in the field regarding AS as a separate diagnostic entity, it is important to note that several prominent researchers in the field, many of whom have at some point questioned its validity, have been acknowledged in the DSM as being significant contributors to the AS field trials. While this fact does not resolve the controversy, it does suggest that there are many individuals who support the inclusion of AS in the DSM. Regardless of one's stance on this topic, the fact remains that AS currently is recognized as a separate condition and as a result should be studied separately in order to obtain as much information as possible regarding those individuals who have received this diagnosis.

Reported prevalence rates for AS vary from 0.03 to 6.0 per 1,000 (Mattila et al., 2007). Several factors have contributed to this variability. First of all, due to the recent recognition of the disorder in both the DSM-IV and the ICD-10 many adults who may have qualified for a



diagnosis of AS prior to 1981 would not have been provided with the diagnosis. Secondly, the diagnostic criteria for AS in the DSM likely results in a gross underrepresentation due to the fact that it becomes extremely difficult to obtain a diagnosis of AS when strictly following diagnostic guidelines because most often a diagnosis of autism takes precedence (Mayes, Calhoun, and Crites, 2001). And thirdly, according to Howlin and Asgharian (1999), children with AS are generally diagnosed much later than children with autism, resulting in an underestimation of prevalence rates in samples that include young children. Therefore, it has been suggested that older samples of children be examined in order to obtain more accurate data. Mattila et al. found prevalence rates to be 2.9 in 1,000 when examining eight-year-old children.

#### *Purpose of Proposed Research*

Much of the research on adult outcomes for high-functioning individuals with autism spectrum disorders has avoided separating HFA and AS due to the lack of consensus regarding the taxonomic validity of AS. Results have suggested that objective outcomes tend to be poor in a number of areas (Howlin, 2000; Engstrom, Ekstrom, & Emilsson, 2003). However, regardless of whether these groups represent two distinct conditions, it may be important to separate these groups in QOL research because a number of factors, such as language abilities, time of diagnosis (Howlin & Asgharian, 1999), and amount of funding and support (Missiuna et al. 2003; Tantum, 2003; Schopler, 1998; Klin and Volkmar, 2000) likely differ between these two populations. These differences could result in unique experiences which, in turn, could lead to discrepancies between the groups in terms of QOL.

Although research examining objective measures of outcomes in adults with high-functioning autism spectrum disorders has found poor outcomes regardless of diagnosis (Howlin, 2003), it has been recently suggested that in order to obtain more accurate depictions of overall

QOL, subjective impressions must be examined as well (Schalock, 2004). Jennes-Coussens, Magill-Evans, and Koning (2006) found that on subjective measures, adults with AS scored lower than controls on QOL indicators in the areas of physical health and social relationships. Renty and Roeyers (2006) found that the most significant predictor variable of QOL for high-functioning individuals with autism spectrum disorders is support characteristics. In fact they found that one of the most significant factors that predicted quality of life was the discrepancy between support needed and formal support provided. That is, those individuals who had minor discrepancies tended to score higher on QOL measures than those who had large discrepancies between the support they needed and the support that was formally provided to them. The purpose of this research is to examine which formal support variables, if any, relate to subjective QOL scores in four domains (physical health, psychological health, environment, and social relationships) as well as a single-item QOL score and an overall QOL. In other words, the current study was conducted to determine whether any of the specific formal supports measured could improve the lives of adults with AS. For the purposes of this study, it has been assumed that the information provided by the participants is accurate and that those individuals who have reported being diagnosed with AS by a qualified professional or group of qualified professionals, have indeed been appropriately diagnosed.

## CHAPTER 2: LITERATURE REVIEW

### *Chapter Synopsis*

This chapter is intended to provide the reader with a thorough review of the literature in the field of AS, adult outcomes, and quality of life. The chapter begins with an overview of the history of both autism and AS, with brief descriptions of the first documented cases and the more recent interest that has been taken in the area of AS. The chapter includes information regarding the notion of the autism spectrum, differential diagnosis, and the most recent estimates of prevalence rates for AS. The chapter is concluded with a summary of the literature in the area of adult outcomes and quality of life for individuals with autism spectrum disorders followed by a brief description of the current gaps in the research literature and the purpose of the current study. This chapter is followed by a Methodology chapter, in which the details of the proposed study, including demographic information, measurement instruments, and statistical analysis, will be discussed.

### *Historical Context*

In 1943 an Austrian psychiatrist by the name of Leo Kanner described a group of young children he observed that shared a specific set of common characteristics. He described them as being socially aloof and stated that they appeared to be highly dependent on routine. He noted that they were either mute or echolalic with idiosyncratic speech and that they had well developed rote memory or visuospatial skills while displaying a general delay in learning. Kanner chose the term “early infantile autism” to describe this unique set of characteristics. One year later Hans Asperger, unaware of the work of Kanner, described similar patterns of behaviour in older children and adolescents. However, while these two groups had several overlapping characteristics, the individuals that Asperger observed appeared to be higher

functioning. He described this population as being naïve and socially inappropriate with poor motor coordination. He observed that although they appeared to have good speech and were of borderline to superior intelligence, they did not communicate appropriately, had poor intonation and body language, and often had specific learning difficulties. Asperger referred to the peculiar set of characteristics he observed as “autistic psychopathy” (Wing, 1997).

For the next 30 years Asperger’s observations went largely unnoticed and Kanner’s work dominated the field of autism research. However, in 1981 Lorna Wing published a paper on the unique set of characteristics that Asperger had described. In her paper she documented a number of cases of individuals who had been referred for psychiatric services. While the characteristics of these individuals were similar to those that Kanner had described, it was clear that they more closely resembled those individuals described by Asperger (Attwood, 2004). From her observations, Wing concluded that Kanner and Asperger may have been describing two separate, yet related populations (Wing, 1981). As a result she coined the term “Asperger’s syndrome” (AS) to represent individuals who shared the characteristics described by Asperger.

### *Autism Spectrum Disorders*

According to Wing (1997) there are a variety of similar conditions that fall under the umbrella of autism spectrum disorders. Thus, the differences between the characteristics of AS and Kanner’s “classic autism” can be regarded as a matter of the severity of the impairment (Wing, 1981). While the young child with autism typically is socially aloof and indifferent to the presence of others, the AS child appears to be passive or involved in inappropriate social interactions in which they may be dominating conversations with perseverations on specific interest areas. The child with autism is often mute or has specific observable speech abnormalities or developmental delays, whereas the conversational abilities of the child with AS

tends to be precocious in terms of vocabulary and grammar but deficient in the area of pragmatics and comprehension. Wing also points out that with autism, the individual often becomes fixated on objects, developing stereotyped, repetitive routines around them. Those with AS, on the other hand, frequently focus on obscure factual information regarding an area of special interest. In terms of similarities, Wing (1997) has stated that it is widely accepted that all disorders that fall under the autism spectrum are marked by underlying psychological impairments in three areas of functioning: social interaction, communication, and imagination.

The prevailing view at present is that AS is a form of autism and that both conditions lie on a continuum with AS located on the higher functioning side of autism spectrum disorders (Baron-Cohen, 1995; Frith, 1991; Wing, 1981). In fact, Wing has suggested that all of the characteristics of AS and, for that matter autism, can be found in the normal population to varying degrees. Thus, at one end of the spectrum are those severely affected by the unique set of characteristics associated with autism, while at the other end of the spectrum is the normal population with only minor manifestations of autistic characteristics. Wing also suggested that it is possible that an individual could be classified as having AS because their degree of affectedness is significantly atypical in each of the characteristic features of the disorder or simply because one specific feature is so distinctly atypical that it affects their overall functioning. Regardless of the degree to which each characteristic is expressed, it is generally accepted that for those with autism spectrum disorders some form of impairment can be observed in each of three characteristic areas and that in terms of overall functioning AS lies somewhere between Kanner's "classic autism" and the normal population.

The term high-functioning autism (HFA) has also appeared regularly in the literature to describe individuals who seem to be more moderately affected by the disorder than the

individuals described by Kanner. However, unlike AS, HFA is not currently recognized in either the DSM or the ICD-10. The term is presently only used as an informal means of distinguishing those individuals with Autistic Disorder who do have a cognitive impairment from those who do not. Gillberg and Ehlers (1998) have suggested that it may be appropriate to conclude that an individual with autism is high functioning if they meet all the criteria for a diagnosis of autism and their total IQ is above 65-70. This criterion, although stated in the DSM and ICD-10 as an absence of delay in cognitive development, is also one of the distinguishing features of AS. This congruence as well as several other contributing factors, such as the similarities between the groups in terms of adult outcome (Howlin, 2003) and the difficulties in determining legitimate neuropsychological differences (Wing, 1998; Szatmari, 1998), have led many to speculate that HFA and AS may simply be different labels for the same disorder (Schopler & Mesibov, 1998).

### *Differential Diagnosis*

Current diagnostic criteria dictate that it is the absence of a significant language delay during development that distinguishes AS from Autistic Disorder (American Psychiatric Association, 2000; World Health Organization, 1992). According to the DSM and ICD-10, if a language delay is reported to have been present during development, a diagnosis of autism should be given, with the high-functioning label being only an informal means of denoting the individual's cognitive abilities. If the developmental history indicates no sign of language delay but all other criteria for an autism spectrum disorder are met, both the DSM and ICD-10 dictate that AS should be the subsequent diagnosis. However, several researchers in the field have questioned the necessity of having normal language development as a diagnostic criterion for AS (Wing, 1981; Tantam, 1988; Gillberg, 1989; Attwood, 2004). In fact, just under half of the individuals that Wing described in her seminal paper had early language delays and several

researchers have found that the presence of a language delay in development does not significantly discriminate between AS and HFA after the first few years of life. (Howlin, 2003; Gilchrist, Green, Cox, Burton, Rutter, and Le Couteur, 2001; Eisenmajer et al., 1998; Mayes and Calhoun, 2001). Attwood has stated that he believes it is more appropriate to use current language functioning to discriminate between AS and HFA rather than the criteria used in the DSM and at least one study (Manjiviona & Prior, 1995) has used this method in the assignment of participants to AS and HFA groups.

A recent study has provided evidence to support Attwood's position (Kjelgaard & Tager-Flusberg, 2001). Kjelgaard and Tager-Flusberg applied the diagnostic criteria for Specific Language Impairment (SLI) to children with autism spectrum disorders and found that a large proportion of the high-functioning individuals in their sample actually met the criteria for SLI. As a result, they concluded that children with AS may simply be different from those with HFA in that they do not have SLI. Szatmari (2005) suggested that, in light of this evidence, it may be more appropriate to distinguish between AS and HFA based on the presence or absence of SLI rather than early language development. However, if this proposed method was to be used, diagnoses of AS and HFA could not be made until after the age of six when deficits in language development are more obvious.

Although the DSM is often perceived as the gold standard in diagnosis amongst professionals in North America, Lorna Wing (2005) stated that its diagnostic criteria for AS are actually the least similar to the descriptions originally provided by Asperger. Furthermore, Mayes, Calhoun, and Crites (2001) found that if strict DSM-IV diagnostic criteria were applied it became virtually impossible to diagnose AS due to the fact that in most cases a diagnosis of autistic disorder would take precedence due to the degree or number of deficits in the area of

communication. In fact, Miller and Ozonoff (1997) discovered that according to the DSM criteria, none of the four cases that Asperger described in his original paper would have received a diagnosis of AS. However, Szatmari, Bryson, Streiner, Wilson, Archer and Ryerse (2000) pointed out that there is actually no empirical data to support the precedence rule included in the DSM. Attwood (2007) stated that the current diagnostic criteria of choice for many clinicians, especially in Europe and Australia, are those of Gillberg and Gillberg (1989), which allow for the possibility of a language delay during development. Although Asperger believed that a language delay excluded an individual from his grouping, according to Attwood, it is the set of criteria developed by Gillberg and Gillberg that are the closest to Asperger's original descriptions and best represent the profiles of individuals who are most often referred for an assessment of AS.

Research conducted in England and Australia regarding the diagnostic procedures of clinicians has provided evidence to support Attwood's (2007) claim that some clinicians may prefer other diagnostic criteria over the DSM and ICD-10 (Eisenmajer et al., 1996). Researchers found that the diagnoses of autism spectrum disorders are often based on factors other than the criteria set out by the DSM or ICD-10 (Eisenmajer et al., 1996; Pomeroy, 1998). For example, Eisenmajer et al. found that many clinicians believed it was more appropriate to diagnose children with AS when they appeared to be less socially impaired, regardless of whether language delays were noted in their developmental history. According to the authors of this study, this may have been due to the fact that these individuals were perceived to be more similar to the accounts provided by Asperger and other prominent researchers who have documented cases of AS. This lack of consensus in diagnostic practice as well as subsequent inconsistencies in research methodology, the fairly recent recognition of AS, and the improbability of reaching a



diagnosis of AS when following DSM criteria (Howlin, 2000) have proved to be extremely problematic for anyone attempting to examine differences between the two groups, as many of the diagnoses as well as research conducted to date have been influenced by these issues (Howlin, 2000; Mattila et al., 2007).

In light of this possibility, some of the research employed explicit and specific diagnostic criteria in their methodology. Klin, Volkmar, Sparrow, Cicchetti, and Rourke (1995) used strict diagnostic criteria based on ICD-10 research, in their study to separate groups rather than relying on prior diagnoses. Their findings have provided evidence to suggest that there may actually be a distinct neuropsychological difference between individuals with HFA and those with AS. They found that while overall IQ scores were comparable, IQ profiles were remarkably different. Individuals in the AS group showed large discrepancies in favour of Verbal IQ (VIQ) over Performance IQ (PIQ), whereas the HFA group, on average, showed significant differences favouring PIQ scores. These findings support the hypothesis put forth by Klin et al. that the AS IQ profile is more similar to that of an individual with a Nonverbal Learning Disability (NLD) than the HFA profile. This, in turn, may provide some credence to the theory that at the higher functioning end of the autism spectrum there are two separate conditions with two distinct neuropsychological profiles: AS with primarily right hemisphere dysfunction and HFA, a condition associated mostly with left hemisphere dysfunction (Tsai, 1992).

In addition Klin et al. (1995) also compared the HFA and AS neuropsychological profile by examining the likeness of the two groups to NLD characteristics on 22 items that were considered to be typical of the NLD profile. These items included seven areas of positive features as well as 15 deficit areas. The results suggested a high degree of concordance between AS and NLD, with 11 out of 22 items having significant differences. However, Wing (1998)

pointed out that for each of the items examined there were some individuals that had results that were more common in the other group, suggesting that individuals with AS and HFA could both present with NLD characteristics. Furthermore, Wing brought attention to the fact that the criteria used in this study to situate participants in the AS group may have inadvertently contributed to the high rates of concordance. Included in the stringent criteria used by Klin et al. to designate inclusion in the AS group are the presence of motor clumsiness and delayed motor milestones as well as the absence of significant language or cognitive delays during development. It is therefore, not surprising that the AS group scored higher on the NLD characteristic items that included clumsiness and verbal output and articulation.

In a further attempt to critique these findings Szatmari (1998) stated that although motor clumsiness has often been referred to in the literature as a possible distinguishing characteristic of AS, and the ICD-10 and DSM have also referred to it as a common characteristic, no empirical data, to date, has been presented to support the notion that it is more common in individuals with AS compared to those with HFA. Using this characteristic as one of the distinguishing criteria then, may pose a problem in research attempting to determine diagnostic differences. This factor alone, Szatmari suggested, could contribute to at least some of the differences found in the scores on the NLD items. Furthermore, it could be hypothesized that the selective criteria used in this study regarding motor clumsiness may have also contributed to the differences in Performance IQ scores as well, considering individuals with poor motor coordination are likely to score lower in tasks that assess visual-spatial abilities.

While it is possible that the discrepancies in Performance IQ could be accounted for by the selection procedures used in the Klin et al. (1995) study, differences in Verbal IQ scores cannot be explained in the same manner. The inclusion of the absence of a language delay during

development as a distinguishing characteristic of AS is in accordance with the criteria set out by both the DSM and ICD-10 and as such, is at present the major distinguishing feature of AS. In fact, in a comparative study of children with AS and HFA, using DSM criteria only, Ghaziuddin and Mountain-Kimchi (2004) partially replicated the results of the Klin et al. study, finding that individuals with AS, on average, do have significantly higher VIQ's as well as significant discrepancies favouring VIQ over PIQ. However, in this study, no significant differences were found between the groups in PIQ scores and no significant discrepancy between PIQ and VIQ was found in the HFA sample. These results appear to support the previous finding that individuals with AS, on average, have higher VIQ's than those with HFA. However, they may also support the hypothesis that the inclusion of motor clumsiness as a distinguishing feature in the Klin et al. study contributed to the differences in PIQ scores. Discrepancies between AS and HFA on one specific PIQ task was observed in a study examining the cognitive profiles of 120 Swedish children with HFA, AS, and attention disorders. Ehlers et al. (1997) demonstrated that while individuals with AS tend to excel in areas measuring verbal abilities, those with HFA on average have stronger performances on the Block Design task of the WISC-R, a measure of visual spatial ability. However, the selection procedures of this study were not consistent with the previous two and included both language delay and motor clumsiness as possible characteristics of the AS group, leaving some doubt around whether the visual spatial ability differences observed were, like the Klin et al. study, influenced by the possibility of clumsiness as a distinguishing feature of the AS group. What is of particular interest in the results found in this study, is that despite the fact that the selection procedure did allow for language delay in the AS group, language ability still came out as a significant discriminating factor. However, the

authors of this study did state that only three of the forty participants with AS had delayed language development.

Although these results may, at face value, appear to provide evidence of taxonomic validity (a type of validity that is used to address the legitimacy of having a distinct categorical representation for a disorder; evaluated through comparative studies between the disorder in question and other related conditions) for AS given the differences in IQ profiles, it should be noted that there is a degree of circular reasoning in these findings considering that the outcome variable was often closely tied to the major criterion for group assignment in two of the studies and that the third had a vast majority of the individuals in the AS group meet the same criterion. According to Klin (1994 as cited in Klin et al., 1995), this circularity, along with a lack of consensus regarding diagnostic criteria for AS, has resulted in mixed findings in the research. Szatmari et al. (2000) suggested that in order to avoid these circular findings and to provide evidence for the validity of AS, research must be conducted using outcome measures that are distinct from the initial criteria used for the assignment of groups. Thus, if language delay is the main differentiating criterion in the research, then language measures or any dependent variable highly correlated with language should not be used as the sole outcome variable. As a result of this apparent shortcoming in the research, several studies have attempted to investigate factors seemingly unrelated to language abilities in order to examine possible differences between AS and HFA. However, the results of these findings have been conflicting.

Miller and Ozonoff (2000) used DSM criteria to study several variables that were thought to possibly differentiate the disorder, including intellectual profiles, motor impairment, visuospatial skills, and executive function, to determine differences between individuals with HFA and AS. They found that overall, the AS group had higher Full Scale IQs and that once

overall intelligence levels were controlled, a large majority of the differences between the groups disappeared. The authors suggested that this result may actually indicate that the most obvious discriminating feature between these two PDD subtypes is overall intellectual functioning, simply making AS a “higher-IQ autism” (p. 235). They suggest that the result of this finding may imply that while it appears that there is a measurable difference between these two PDD subtypes, the status of AS as a separate condition may not be warranted.

However, several studies that have examined a number of different variables have found differences that may provide evidence for the taxonomic validity of AS, though it is unclear the extent to which the results relate to the discriminating criterion. A recent study comparing neuroanatomical differences between children with low-functioning autism (LFA), AS, and HFA found that cerebral grey matter was significantly enlarged in individuals with LFA and HFA as compared to those with AS and controls (Lotspeich et al., 2004). While the AS group did not show significant enlargement, it did mark an intermediate point between HFA and the control sample, suggesting that AS may represent a more moderate form of autism than HFA. Furthermore, differences were also found in the relationship between cerebral matter and PIQ scores. Cerebral grey matter was found to be negatively correlated with PIQ for the HFA sample, whereas a positive correlation was shown between cerebral white matter and PIQ in the AS group.

Discrepancies have also been observed between AS and HFA in outcome studies. Szatmari et al. (2000) found that children with AS who were between the ages of four and six at initial assessment were significantly less impaired than their HFA counterparts at a two year follow-up. After two years, the children with AS in this study were observed to have better social skills as well as fewer autistic symptoms than those with HFA, even after initial differences in

language abilities and IQ were accounted for. Szatmari, Bryson, Boyle, Streiner, and Duku (2003) used this same sample to assess the outcome of their participants at 10-13 years of age. Their finding showed that still at this age children with AS, on average, had better outcomes in the areas of socialization and communication as well as lower scores on autistic symptoms. It is important to note, however, that language was found to be a better predictor of outcome for the HFA group than for those with AS. The authors suggested that this may be due to the fact that HFA and AS represent different, yet related, developmental trajectories in which language is the main distinguishing feature. It may be possible for individuals with HFA to join the advanced AS developmental pathway if they develop fluent language in a timely manner. However, the longer it takes them to develop language the farther behind they will be on this pathway. While they may join the same developmental pathway as that of the AS individuals and therefore resemble children with AS to a large degree if they develop language before the age of six (Szatmari, 2005), they will likely remain behind in terms of development due to their initial language delay. In short, they will be on the same trajectory, only at an earlier stage. This, the authors suggested may explain why the predictive ability of language is greater for the HFA group than the AS group. Although this model remains to be tested, its likeness to some of the early observations of Wing may provide some evidence of its merits. Wing noted that some of the children she observed who had autistic features when they were very young, including language delay, ended up later in life, more closely resembling those individuals described by Asperger (Wing, 1981), suggesting that some individuals who start off life with more severe autistic characteristics can join the developmental trajectory of AS as Szatmari et al. have suggested.

A number of studies have found significant deficits amongst individuals with HFA and AS in tasks involving theory of mind (Baron-Cohen, Leslie, & Frith, 1985; Ozonoff, Pennington,

& Rogers, 1991; Baron-Cohen, Jolliffe, Mortimore, Robertson, 1997; Rutherford, Baron-Cohen, & Wheelwright, 2002), a term used to describe the ability to recognize that other people have thoughts, emotions, and, beliefs that are independent of one's own. However, few have attempted to examine differences between individuals with HFA and AS in this area. Although comparative studies are limited in this domain, Ozonoff, Rogers and Pennington (1991) did find that individuals with AS performed better on theory of mind tasks than individuals with HFA and one study found that individuals with AS were more likely to be successful than those with HFA in a false belief task, designed to assess the participants' ability to understand the mental state of another person (Ziatas, Durkin, & Pratt, 1998). While the findings of these studies appear to suggest an observable difference in theory of mind between individuals with AS and HFA, Dahlgren and Trillingsgaard (1996) found conflicting evidence, suggesting no difference in performance on theory of mind tasks between these groups. However, Ziatas et al. stated that the advanced verbal mental age of the participants in the Dahlgren and Trillingsgaard study may have accounted for their findings. In fact, several studies found strong positive correlations between verbal abilities and performance on theory of mind tasks in individuals with autism spectrum disorders (Eisenmajer & Prior, 1991; Happe, 1995; Ozonoff et al., 1991; Prior et al., 1998). Dahlgren, Sandberg, and Hjelmquist (2003) found that theory of mind deficits do not only exist in individuals with autism spectrum disorders but that they may be common in individuals with any disability associated with impaired communications abilities. These findings may imply that impairment in the area of theory of mind may actually be more a representation of general language deficits than a valid discriminating feature of Pervasive Developmental Disorder (PDD) subtypes.

Although several differences between AS and HFA have been found in children and adolescents when DSM diagnostic criteria are used, Howlin (2003) found that when examining adults using identical distinguishing criteria regarding language development, there were very few differences. In fact, only small significant differences were observed between groups in scores on language-based measures, suggesting that the differences between the neuropsychological profiles of AS and HFA may actually decrease with age. It is interesting to note, though, that the instruments used in this study to measure language resulted in ceiling effects for both populations. Thus, age equivalent scores were used in place of standard scores, calling into question the appropriateness of the instrument for this particular population. Nevertheless, Howlin has used this data to suggest that it is unlikely that language differences are indicative of any true diagnostic split between AS and HFA. Rather, she believes that the observed differences in the two adult populations are simply a result of the effect of the initial differences in language development. She suggested that this may mean that adults with HFA present with relative weaknesses in terms of language abilities as compared to their AS counterparts simply due to the fact that they are at disadvantage right from early childhood. If Howlin is correct in her assumption, this may also account for the inconsistencies in the theory of mind research regarding differences between individuals with AS and HFA across different verbal mental ages.

Howlin (2003) is by no means alone in her belief that the differences between individuals with AS and HFA diminish over time. Additional evidence for this theory has been provided by Gilchrist et al. (2001). They found that although children with AS were perceived by parents to be less impaired than those with HFA early in life, by adolescence, impairments were observed to be comparable between the two groups. Similarly, Eisenmajer et al. (1998) found that while



language delay appeared to predict autistic symptoms in very young children, no such differences were present for older children, suggesting that some of the differences between groups appear to decrease with age. Eisenmajer et al. have proposed that these results may provide evidence that call into question the appropriateness of early language delay as a discriminating characteristic between AS and HFA and Prior et al. (1998) have found results that have also challenged the validity of language development as a discriminating criterion. In fact, even in a study of young children, in which 71 variables, including autistic symptoms and expressive language, were examined, Mayes and Calhoun (2001) found no significant difference between high-functioning children on the autism spectrum who did have an early language delay and those who did not.

Although several researchers have expressed disapproval with the inclusion of AS in the DSM and ICD-10, numerous studies have documented differences between AS and other PDDs. However, despite this, controversy remains due to the inconsistencies in sampling, the conflicting findings, and the possibility of circularity in many of the results of the research conducted to date. While research has yet to clearly validate AS as a separate diagnostic entity, what it has provided is evidence of the fact that there is a group of high-functioning individuals with autism spectrum disorders who likely have had distinct childhood experiences due to their unique combination of intellectual profiles and social difficulties.

Howlin (2003) found that regardless of diagnosis most individuals on the higher-functioning end of the autism spectrum tend to show poor adult outcomes on a number of variables examined including employment, friendships, and independent living. Despite this, several authors have indicated that the AS label, as opposed to a diagnosis of autism, may actually result in less funding and support (Schopler, 1998; Klin and Volkmar, 2000; Missiuna et

al., 2003). In Canada, priority for services for children tended to be geared towards those with more severe disorders as well as younger children (Missiuna et al.). Considering the fact that individuals with AS tend to be diagnosed later than those with autism (Howlin and Asgharian, 1999; Missiuna et al., 2003) and, by definition, are of average to above average intelligence (American Psychological Association, 2000), it is likely that many individuals with AS are deprived of the early support given to those with a diagnosis of autism. Furthermore, there has been indication that the funding practices regarding IQ may be similar for adults in some locations (Autism Ontario, 2008). However, Autism Ontario has suggested that the needs for individuals with autism spectrum disorders who do not have intellectual disabilities are as great as those who do. Thus, basing government funding solely on intelligence levels is essentially depriving individuals with AS from receiving the support that they need.

Regardless of whether AS and HFA truly are distinct subgroups on the autism spectrum, the fact that individuals with a diagnosis of AS have reportedly been deprived of some of the support given to those with a diagnosis of autism is cause for concern considering the poor outcomes observed amongst individuals in this population. Howlin (2000) stated that while some individuals with AS do have more positive adult outcomes, these cases are rare and almost never come easily. For most individuals on the higher functioning end of the autism spectrum, in order to find employment or accommodation they need to rely heavily on the support of their families (Howlin, 2000). While, Howlin believes that it is early intervention that is the key to minimizing secondary behavioural problems so that the skills of these individuals can be developed to their full potential, several studies have also shown that support in adulthood can be beneficial as well (Howlin & Yates, 1999; Mawhood & Howlin, 1999). However, in order to determine what types of support are best suited to those individuals who have been diagnosed with an autism spectrum

disorder but have had unique experiences due to their intellectual and verbal abilities, AS needs to be separated from other autism spectrum disorders in the research.

### *Prevalence*

Recent research has indicated that the prevalence rates for AS vary from 0.03 to 6.0 per 1,000 (Mattila et al., 2007) depending on methodological and sampling procedures. Several factors may account for this discrepancy. First of all, epidemiological studies of AS are in their infancy due to the recent recognition of the disorder in both the DSM-IV and the ICD-10. Secondly, as mentioned above, when followed strictly, the diagnostic criteria for AS in the DSM likely results in a gross underrepresentation due to the precedence that a diagnosis of autism takes over AS (Mayes, Calhoun, and Crites, 2001). Furthermore DSM-IV and ICD-10 criteria are often ignored by practitioners, resulting in inconsistencies in epidemiological data (Klin, et al., 1995; Howlin, 2000). And thirdly, according to Howlin and Asgharian (1999), children with AS are generally diagnosed much later than children with autism, resulting in an underestimation of prevalence rates in samples that include young children. Fombonne (2001) therefore, has suggested that in order to obtain more valid estimates of prevalence it is imperative that slightly older samples be examined. According to Mattila et al., epidemiological studies that have targeted older children have resulted in higher prevalence rates. In fact, in their study of eight-year-old children, using four separate categories of strict diagnostic criteria, Matilla et al. found prevalence rates to be as high as 2.9 in 1,000.

### *Adult Outcomes*

Because of the difficulties with differential diagnosis many of the studies, to date, have included both HFA and AS in their research without attempting to examine differences between the two groups. As mentioned earlier, Howlin (2003) found that outcome tends to be poor

regardless of diagnosis. In a recent review of the research literature regarding adult outcome for high-functioning individuals on the autism spectrum, Howlin (2000) found that results were extremely variable across studies. For example, in the studies she reviewed the percentage of individuals in paid employment ranged from 5% to 55%, while those with post-secondary degrees or diplomas ranged from 7% to 50% and those living in semi-independent or dependent living arrangements varied from 16% to 50%. While the reasons for the discrepancies in the results can only be hypothesized, it is interesting to note that even if one were to only examine the most optimistic of the results, most outcome variables would still appear to be poor in comparison to the overall population. What is also staggering about the studies reviewed by Howlin was that regardless of the outcomes in other aspects of their lives, the number of individuals with AS who were married was consistently very low, with half of the studies reporting no married participants and the largest proportion of any study being two out of fourteen participants. Engstrom, Ekstrom, and Emilsson (2003) found that most individuals with AS have difficulty finding a spouse and research has also indicated that many high-functioning individuals on the autism spectrum lack close friendships (Howlin, Goode, Hutton, & Rutter, 2004).

The variability in the results reviewed by Howlin (2000) may be partially explained by the findings of Howlin, et al. (2004). Although the only inclusionary criteria, other than the autism diagnosis used in their study was a PIQ of at least 50, their findings suggested that the ability to function as adults was highly dependent on the amount of support offered by families, employment agencies, and social services. Furthermore, they found that overall intelligence was also predictive of outcome with several of the variables they examined. Thus, if the assumption that AS is simply just a “high IQ autism” as Miller and Ozonoff (2000) have theorized, one could

assume that individuals with AS might fare better than those with HFA in terms of adult outcome. However, recent research on the quality of life for adults with specific diagnoses of AS has painted a bleak picture.

Several studies have found that many adults with AS do not live fully independent lives (Howlin, 2000) and many struggle to find and maintain permanent, meaningful employment that is commensurate with their abilities (Hurlburt & Chalmers, 2004; Howlin, 2003; Engstrom et al., 2003). Barnhill (2007) has indicated that while individuals with AS often have the technical skills required to adequately perform a job, they often are unable to obtain employment because they fail to engage in the appropriate reciprocal conversations that are necessary to succeed in job interviews. Furthermore, Barnhill pointed out that even when individuals with AS are successful in obtaining employment they often struggle to keep their jobs due to difficulties with social skills. Hurlburt and Chalmers reported that individuals with AS most often cited poor communication between employee and employer or coworkers, poor social skills, and sensory sensitivities to be the most significant challenges that they face in terms of maintaining jobs. Good, Rutter, and Howlin (1994 as cited in Barnhill, 2007) suggested that the cognitive abilities of individuals with AS may actually make them more susceptible than those with more severe autism spectrum disorders to the stress and disappointment that comes with their employment failure.

Several studies have found that comorbid mental health conditions are frequently observed in individuals with AS (Wing, 1981; Gillberg, 1985; Ghaziuddin, Weidmer-Mikhail, & Ghaziuddin, 1998). Ozonoff, Garcia, Clark and Lainhart (2005) found that when using the Minnesota Multiphasic Personality Inventory- Second Edition (MMPI-2) individuals with AS scored higher than controls in areas related to depression. Similarly Ghaziuddin et al. found that

while ADHD was the comorbid condition most often observed in children with AS, depression was most common in adolescents and adults. Ghaziuddin et al. suggested that the presence of depression may be a result of their difficulties coping with the disorder and the social stigma that is attached to this inability to cope. Tantum (2003) suggested that anxiety may actually be the most common and persistent disorder associated with all PDDs and several studies have reported high incidences of both bipolar disorder and anxiety disorder in individuals with AS (Ghaziuddin et al., 1998; Tantum, 2000). Considering the high incidences of mental health problems amongst individuals with AS it is not surprising that suicide rates in this population are also significantly elevated (Wing, 2000).

Issues regarding physical health problems have also been documented in the research examining individuals with AS. A recent study measuring four areas of quality of life found that individuals with AS scored lower than controls in both the social and physical health domains (Jennes-Coussens, Magill-Evans, & Koning, 2006). Participants in this study cited discomfort and pain, dependence on medication, energy, fatigue, and mobility as some of the areas of physical health with which they were unsatisfied. In addition, Oyane and Bjorvatn (2005) found that it is common for adolescents and young adults with autism and AS to also suffer from significant sleep disturbances. However, whether this is a symptom of autism spectrum disorders or simply a result of comorbid condition is yet to be determined. Several studies have also documented difficulties individuals with AS have with sensory overstimulation (Barnhill, 2007) and MacFabe et al. (2007) pointed out that many individuals on the autism spectrum also suffer from chronic abdominal pain due to abnormalities of the gastrointestinal system.

In 2001 the National Autistic Society of Britain released a report entitled *Ignored or Ineligible* (Barnard, Harvey, Potter, & Prior), in which the results of a UK-wide survey, sent out

to 1200 parents of adults with an autism spectrum disorder, were summarized. The report was in response to a proposal released by the British government to address the needs of individuals with cognitive impairments. The proposal, however, excluded any individual with an autism spectrum disorder who did not have an accompanying intellectual deficit, essentially disenfranchising over half of the people on the spectrum. The findings of the survey were divided into four main categories to correspond with the four key principles central to the government's proposal to address the needs of individuals with cognitive impairments. These four principles were: rights, independence, choice, and inclusion. The results of the survey indicated similar outcomes for individuals with AS that have been documented in the literature, and supported the notion that the needs of individuals on the autism spectrum, especially those on the higher-functioning end of the spectrum, are far from being met in these four areas.

### *QOL Research*

In the last three decades the concept of QOL has been used increasingly in the research in a number of fields including health, education, and social services. Stedman (1996) pointed out that it was during a campaign speech in 1964 by American President Lyndon Johnson that the term QOL was first introduced to the world when he stated that "Goals cannot be measured in the size of our bank balance. They can be measured in the quality of the lives that our people lead." However, Shalock (2000) reported that it was not until the "quality revolution" of the 1980's that the term "quality of life" started to be embraced in the field of disabilities work. During this time a major paradigm shift that favoured quality products and services was occurring in the business world in the United States. The success of companies that had adapted their businesses to meet this change was apparent and as a result, those employed in the field of disabilities work began to take on a similar philosophy. The concept of QOL soon became the

overarching principle in the field with the goal of QOL enhancement as the theme for service delivery and programmatic change.

Although the concept of QOL had been fully embraced by the 1990s, consensus around the definition and the measurement of it had not yet been reached. In fact, according to Schalock (2000), by the year 2000 there were over 100 different definitions of QOL that could be found in the literature. Thus, much of the 1990's was dedicated to answering a number of questions regarding QOL, including what exactly is the best definition of QOL, whether it is a single entity or a multidimensional construct, how best to conceptualize the indicators, and what criteria need to be considered in its measurement (Schalock, 2000).

Although, there is still a lack of agreement in the field over the definition of QOL (Skevington, Lofty, & O'Connell, 2004) and several different models have been developed to represent the construct (Schalock, 2004), there is now consensus that both multidimensionality and subjectivity are essential aspects of QOL (Cella, 1998 as cited in Henrich & Herschbach, 2000; Schalock, 2000; Schalock, 2004). The term "multidimensionality" has been used by several authors to refer to the fact that any proposed model of QOL should recognize the different aspects of life that comprise the life experience (Schalock, 2004; Henrich & Herschbach, 2000). However, as Cummins (1996) pointed out, if each aspect of the life experience is regarded as separate in the measurement of QOL, the number of domains would be very large. A more practical approach then would be one in which the shared variance of many of the terms would be utilized and as a result a small set of domains representing the entirety of the human experience could be employed. A review of the literature on QOL found that while over 100 indicators of QOL had been used in the research, the vast majority of them related to eight domains: interpersonal relations, social inclusion, personal development, physical well-being,



self-determination, material well-being, emotional well-being, and rights (Schalock, 2004).

Internationally, there is now a broad consensus regarding the legitimacy of this eight-factor multidimensional model (Renty & Roeyers, 2006).

Over the past few decades, professionals in the field of health care have also begun to acknowledge that traditional objective health indicators such as mortality and morbidity may not provide adequate information regarding overall health status or QOL (Skevington, Lofty, & O'Connell, 2003). According to Cummins (2000), although QOL has traditionally been measured by objective standards, research shows only small correlations between objective measures and overall life satisfaction, whereas correlations amongst different objective measures and correlations between various subjective measures tend to be higher. As Cummins points out the reasons for these higher correlations between different objective measures, such as education and income, is that many of these variables tend to be influenced by key underlying factors. For example, individuals who have higher levels of education tend to have higher incomes and as a result also tend to have better overall health due to their ability to pay for premium health care, eat healthier, and take time away from work. The relationships between subjective measures also usually follow a similar pattern. Individuals who report being happy, are more likely to be satisfied with their lives, and therefore are less likely to suffer from mental health concerns such as depression. However, the reasons underlying the findings, that objective and subjective measures usually have very low correlations, is much more complex.

According to Headey and Wearing (1989), this can be explained by the fact that people may have a “set point” at which their subjective well-being normally rests. They found that although negative events usually resulted in a decrease in reported levels of subjective well-being for a short time afterwards, the effects of these events generally did not last. That is, they

found that people tended to return to their “set point” of well-being, a point largely determined by age and personality characteristics (Headey & Wearing). Cummins (2000) reported that this finding has also received support from more recent research. However, what Cummins points out that is most important is that while it appears that subjective well-being is maintained mainly by cognitive factors and thus is independent from objective variables, this cognitive homeostasis may be susceptible to the effects of chronic negative objective factors, such as prolonged unemployment (Hepworth, 1980), chronic stress (Christensen, Stephens, & Townsend, 1998 as cited in Cummins, 2000), and spinal injury (Fuhrer, Rintala, Hart, Clearman, & Young, 1992 as cited in Cummins, 2000). In fact, two separate studies (Glatzer, 1991; Diener, Sandvik, Seidlitz, & Diener, 1993) found strong relationships between income and subjective measures of happiness and well-being only for those at the lowest income levels, suggesting that the influence of this particular objective measure is most apparent for those who are subjected to chronic financial difficulties. In light of this evidence, Cummins proposed that it could be inferred that only when objective conditions of living are significantly poor do the correlations between objective and subjective measures reach notable levels. Thus, a change in objective standing will have a disproportionate effect on individuals at lower levels as compared to those whose objective well-being is higher. For example, while a significant increase in annual income will likely not result in a higher reported degree of well-being for the majority of people, for those at the lowest end of the economic spectrum it is more likely to have a significant influence on their subjective well-being. Given the complexity of these relationships and the low correlations between objective and subjective measures of QOL for the majority of people, it is not surprising then that there has been a push in QOL research to use objective and subjective data together in determining overall QOL.

Further support for the importance of subjective measures of QOL has been provided by research conducted in the health related fields. In the past few decades there has been a growing interest in the subjective well-being of patients following medical care and a number of studies have indicated significant discrepancies between objective measures of health and patients' own reports of their well-being (Kawaga-Singer, 1993; Padilla, Mishel, & Grant, 1992; Suurmeijer, Reuvekamp, & Aldenkamp, 2001). As a result, a new approach to health care has emerged with the concept of health-related QOL as the focus (World Health Organization, 1999). This particular focus is entrenched in the notion that objective health measures alone have been inadequate in representing the effectiveness of various medical interventions. While objective measures are valuable in that they can accurately depict the presence or absence of symptoms, only subjective reports can provide insight into the overall influence a specific disorder or intervention has on a patient's energy levels, self-confidence, social life, and overall functioning at work and home (Trompensaars, Masthoff, Van Heck, Hodiament, & De Vries, 2006; Gladis, Gosch, Dishuk, & Crits-Cristoph, 1999), much like how only subjective reports can uncover true overall satisfaction with life. This new approach to health acknowledges the idea that QOL is a subjective, multidimensional construct (Trompensaars et al.).

### *QOL Measurement*

The World Health Organization's (WHO) most recent definition of QOL reflects this new approach. The WHO stated that QOL is “an individual's perception of their position in life in the context of the culture and value systems in which they live, and in relation to their goals, expectations, standards and concerns” (WHOQOL Group, 1998). In measuring QOL then, the WHO has taken the stance that it is of the utmost importance to understand how satisfied people are with various aspects of their lives. These various aspects have, in the measurement of QOL,

traditionally been grouped into a set of factors designed to represent the different aspects of the entire human experience. While there have been a number of different labels used for these factors, Schalock (2004) found that the majority of them did relate to the eight core QOL domains mentioned earlier. Schalock defined the term “domain” as a “set of factors composing personal well-being” (p. 205) and suggests that although QOL models may differ in terms of the domains used to represent the construct as a whole, what is of most importance is that the set of domains employed in any given model represents QOL in its entirety. Schalock has stated that on QOL measures incorporating the eight broad areas, there is no doubt that individuals with intellectual disabilities and other disabilities regularly score lower than controls.

In contrast to QOL domains, Schalock (2004) defined QOL indicators as “domain-specific perceptions, behaviours, or conditions that give an indication of the person's well-being” (p. 205). These indicators are in the process of being operationalized and can be conceptualized as the individual items that relate to and make up a domain. Current research in this area focuses on ensuring that the selection of indicators in QOL research is based on their degree of relatedness to specific domains, their validity, their reliability, their sensitivity, their specificity, and whether the measurement of them is affordable, timely, culturally sensitive, and whether they can be evaluated longitudinally.

Recently the World Health Organization developed a survey to measure quality of life (WHOQOL Group, 1998) as well as a brief version of the survey (WHOQOL-BREF) to provide a more accessible means of gathering data on the concept of quality of life for use in the presence of time constraints or when the minimization of participant burden is deemed to be of high priority (Skevington, et al. 2004). The World Health Organization Quality of Life (WHOQOL) survey is divided into four domains determined by factor analysis: physical health, psychological

health, social relationships, and environment. Jennes-Coussens et al. (2006) used the WHOQOL-BREF questionnaire to measure the quality of life in a group of adult men diagnosed with AS and found that they reported significantly lower than controls in the physical and social domains but not on the environment and psychological domains. However, samples sizes used in the study were extremely small, as is often the case with this population. Thus, it is difficult to determine whether the results of this study are truly representative of the entire population of adults with AS or if they more accurately depict the perceptions of a small percentage of these individuals. In order to gain a clearer understanding of how individuals with AS tend to perceive their QOL, it is imperative that further research conducted in this area employ larger sample sizes so that the results can be generalizable to the entire population of people with AS.

### *Support and Quality of Life*

Although most of the research on quality of life for adults with AS, at present has been focused on descriptive information pertaining to specific outcomes, such as employment and social inclusion and within-person predictive variables such as IQ, recent efforts have been made to examine environmental predictors. Ruble and Dalrymple (1996) suggested that research investigating environmental factors may actually be more valuable since they are easier to control. In accordance with this philosophy, Renty and Roeyers (2006) examined the predictive ability of disability and support characteristics in a sample of high-functioning adults on the autism spectrum and found that while disability characteristics did not explain a significant amount of variance over and above demographic variables, support characteristics alone accounted for 51% of the variance. That is, individuals who perceived a high level of informal support generally rated their QOL significantly higher than those who perceived less support. Furthermore, discrepancies between needed and received formal support were also indicative of

QOL. Individuals who had large discrepancies between support needed and support received consistently scored lower on the QOL measures employed in the study.

While it is important to acknowledge the trends in adult outcome in regards to specific domains, it may be more valuable to consider the positive effect support characteristics can have in influencing quality of life for individuals with AS. In fact, support in the areas of social skills (Howlin & Yates, 1999) and employment (Mawhood & Howlin, 1999) have both resulted in more positive outcomes for individuals with AS. Yet, it has been reported that having a diagnosis of AS can sometimes result in a lower level of support than is offered to individuals diagnosed with Autistic Disorder (Schopler, 1998; Klin and Volkmar, 2000) and as mentioned earlier, Missiuna, et al. (2003) have found that in Canada there are similar concerns. However, Howlin (2003) suggested that, in terms of adult outcome, there is little evidence to support the view that individuals with AS should be provided with any less support than those diagnosed with autism. Furthermore, Tantam (2003) suggested that often an IQ over 70 can be the determining factor that limits support. This is problematic because by definition this criterion would exclude individuals with AS (DSM-IV-TR, American Psychiatric Association, 2000) from some levels of support. However, as indicated by the literature, it is possible that individuals with AS may benefit greatly from an increase in support. In order for this to happen it is imperative that the needs of these individuals be assessed in a systematic manner in order to determine where changes in formal support may be most beneficial.

### *Purpose of Current Study*

The purpose of the proposed research was to collect data from adult members of Asperger's Manitoba Incorporated who have been diagnosed with AS, to gain insight into the current QOL in this population as well as what formal support factors and demographic variables, if any, are related to the different areas of QOL that have been determined by the World Health Organization. The data collected

for this study will be used to increase awareness of the present QOL for adults with AS and those formal support factors that have an influence. In other words, the current study was conducted to determine whether any of the specific formal supports measured could improve the lives of adults with AS. For the purposes of this study, it has been assumed that the information provided by the participants is accurate and that those individuals who have reported being diagnosed with AS by a qualified professional or group of qualified professionals, have indeed been appropriately diagnosed. Thus, it is assumed that the individuals who participated in this study were indeed adults with AS who, at the time of the study, were living in Manitoba.

Although there is still an ongoing debate over the taxonomic validity of AS, it is important to note that several prominent researchers in the field have been acknowledged in the DSM for their contributions to the work that led to the inclusion of AS. Furthermore, research regarding differential diagnosis has continued since the DSM field trials for AS and several studies have found significant differences between AS and HFA. However, regardless of these results, the fact remains that AS is currently included as a separate condition in the DSM and, at present, the DSM is the most referenced diagnostic manual in North America. As a result many individuals have been and will continue to be given this diagnosis. Although it is not clear yet whether AS warrants its status in the DSM, what is clear is that due to a number of diagnostic criteria and environmental factors individuals with AS do represent a population that is likely, in some way, different than those with other PDDs. Thus, it is imperative for their well-being that AS be separated in the research to determine what their current perceptions are of their own QOL and what environmental factors are influencing these perceptions.

### *Conclusion*

This chapter examined the current literature in the field of AS and QOL. Issues surrounding differential diagnosis between AS and other PDD's were explored and an argument

was presented in favour of studying AS as a separate diagnostic entity. Research findings regarding AS and objective outcomes were also presented in this chapter. However, it was pointed out that the current focus in the field of QOL research is aimed at the importance of subjective impressions of QOL over objective measures and thus, a new approach needs to be taken towards determining QOL for this population. A summary of research in the area of AS and objective outcomes as well as AS and subjective QOL studies was presented and the purpose of the current study, to determine whether any formal supports measured improve the lives of adults with AS, was introduced.



## CHAPTER 3: METHODOLOGY

### *Chapter Synopsis*

This chapter outlines the details of this study, including information regarding the research participants, the research methods employed, and instruments that were used in the collection of data. The chapter is concluded by a section discussing the statistical analyses that were used to analyze the data. This chapter is followed by a Results chapter, where the results of the study have been summarized.

### *Sample*

Fifty-six individuals were recruited, via email, from a list of 389 individuals who are members of Asperger's Manitoba Incorporated (AMI), a non-profit organization out of Winnipeg, Manitoba that provides education and advocacy for individuals with AS in Manitoba. Of the 56 individuals recruited for this study, 37 met inclusion criteria for the study and were provided access to the online survey. However, of the 37 individuals who met the inclusion criteria, only 33 (24 male; 8 female) completed the full survey. Of those who did not meet the inclusion criteria for the study, 18 were excluded because they indicated that they did not have a diagnosis of AS themselves but rather were family members or friends of individuals with AS. One individual was excluded from the study because they had indicated that they were self-diagnosed as opposed to having being given a diagnosis from a qualified professional. Four individuals who met criteria to participate in the survey withdrew from participation prior to completing the survey. One completed survey was deleted and therefore, not included in the results, due to the fact that two of the completed surveys were entered from the same IP address within a matter of minutes. Examination of the collected data from these entries revealed that the

responses on the two completed surveys were identical and therefore, it was deemed highly likely that the responses came from the same individual.

AMI currently provides services to individuals with AS and family members throughout all of Manitoba. While AMI's mandate is to serve individuals throughout the province, it has been estimated that a large proportion of registered members are currently residing in the Winnipeg area. The most recent census conducted in 2006 indicated that the current population of Winnipeg (633, 451) is approximately 55% of the total population of Manitoba (1,148,401) (Statistics Canada, 2006). In contrast, of the 33 participants included in this study 27 indicated that they currently reside in Winnipeg, a proportion of approximately 82%, indicating that the participants in this study may not be necessarily representative of the overall population of adults in Manitoba with AS.

### *Procedure*

Prior to contacting potential participants, an ethics application was submitted to the Behavioural Research Ethics Board at the University of Saskatchewan. The ethics application included procedures for contacting participants and explained in detail, that participation was completely voluntary and that participant identities would not be revealed to the researchers. Once ethics approval was received, recruitment of participants began. All members of AMI, excluding government contacts, were sent an initial email requesting participation in the research study. The email included a description of the purpose of the research study, a time estimate for participation in the study, and a website link where potential participants could choose to go to participate in the research. Informed consent was obtained for all participants, via the website, prior to entering the research survey page. Participants were not given access to the survey questions until consent was given. Once consent was obtained participants were directed to an

online 48-item questionnaire followed by the WHOQOL-BREF survey. The survey and questionnaire were completed and submitted online.

Information regarding member status, diagnosis, age, and residence was obtained in the first four items of the questionnaire. Individuals who indicated that they did not have AS, but were family members or friends of an individual with AS, were not included in the data analysis. Individuals who indicated that they did not receive their diagnosis from a qualified professional, such as a physician, psychologist, psychiatrist, or team of any such professionals were not included in the study. Additionally, any participants who indicated that they were either under the age of 18 or currently living outside of Manitoba were also not included in the study. Once it was identified that a participant did not qualify for the study they were directed away from the survey to a page thanking them for their participation and once again explaining that the research was intended for individuals who are 18 years of age or older, have a diagnosis of AS, and currently live in Manitoba. Although the information obtained from these participants was not used in the final data analysis, it was kept for the purposes of the AMI participant database. Participants who indicated that they were 18 years or older, had a diagnosis of AS from a qualified professional, and currently lived in Manitoba were permitted to continue with the questionnaire and survey.

Upon full completion of the questionnaire and survey participants were provided with the option of entering their name in a draw conducted by AMI for a \$100 gift certificate to their choice of either: Futureshop, Walmart, or Superstore. After one weeks of recruitment<sup>13</sup> individuals had fully participated in the study. At this point an amendment to the ethics application was submitted to request permission to send out the recruitment email again. However, this time permission was sought from the ethics board to preface the email with a short

statement indicating that all participants would have the opportunity to enter their name in the draw. After three weeks 26 individuals had fully participated in the study. At this point another amendment was made to the ethics application to receive approval to send out a third, and final, round of participant recruitment following an identical format. After three rounds of recruitment 33 participants fully completed the questionnaire and survey. All information pertaining to the draw was handled by members of AMI and was in no way connected to the research data. All information provided for the draw was kept confidential. Once all of the data was collected the WHOQOL-BREF scores for each participant were scored by hand.

### *Measures*

The following section describes the instruments used in this study to collect data. Two instruments were used: a 48-item questionnaire that was modeled after a survey used by the National Autistic Society in Britain in 2001 and the WHOQOL-BREF.

#### *Questionnaire.*

Participants completed a 48-item self-administered questionnaire that was modeled after the 2001 survey conducted by the National Autistic Society (Barnard, Harvey, Potter, & Prior) entitled *Ignored or Ineligible?* The questionnaire has been modified from its original format in the following ways to reflect the purposes of the proposed research: questions have been deleted for ease of completion and interpretation as well as relevance to the purpose of the proposed study (for example “Do you have an IQ of below 70?”), questions that referred to learning disabilities have been deleted due to inconsistencies in the definition of the term between Britain and Canada as well as the relevance to the population being studied, and questions have been added to obtain ample information on each of the four domains of quality of life as determined by the World Health Organization’s factor analytic findings (for example “Do you have any

chronic pain”) as well as to obtain information on legal issues regarding individuals with AS. The questionnaire was examined and edited by the board members of AMI, including one individual with a diagnosis of AS. The recommendations of the board members led to some minor revisions, including the deletion of one question, regarding mental health concerns, that was deemed to be redundant and the rewording of one other question for clarity.

Items in the questionnaire were used to gather demographic data as well as descriptive statistics on the four domains of quality of life. Demographic data included age, place of residence, gender, origin of diagnosis, age at diagnosis, and comorbid conditions. For several items included in this questionnaire, participants were given the option of choosing “I don’t know.” One item that included this option was the question that asked “Do you currently have a social worker, community health worker, or case manager at this time?” When the data was being analyzed using point-biserial correlations, individuals who answered this way were treated as “no” answers. For items that were included only for descriptive purposes, the number of participants who answered “I don’t know” were reported. Several items in the questionnaire also included an “other” option. Each time a participant selected the “other” option they were provided with space to explain. Each time this happened, the response was reported in the data in the same manner as the rest of the options for the question.

Four items were included in the questionnaire to determine eligibility for participation in the research. The items pertain to whether the participants have AS or are a family member or friend of an individual with AS, the age of the participant, the location of their current residence, and whether their diagnosis was provided by a qualified professional. The remaining items were focused towards the attainment of descriptive data. The questionnaire was sent out to potential participants via a website link in an email and was responded to online.

### *WHOQOL-BREF Survey*

The WHOQOL-BREF was chosen for this study for two reasons. First, it was chosen because it is a common tool used in QOL research and because information regarding its psychometric properties are readily available. Secondly, the WHOQOL-BREF was chosen because the Renty & Roeyers (2006) study that found support characteristics to be the most predictive variables for QOL scores for high-functioning individuals on the autism spectrum also used this specific measure. Therefore, it was chosen to establish a degree of continuity between that study and the current one.

The World Health Organization's Quality of Life – Brief Version survey (WHOQOL-BREF) is a condensed version of the WHOQOL-100. It contains one item from each of the 24 components of QOL included in the WHOQOL-100 (WHO, 1996). The 24 items together, form four domains (physical health, psychological health, environment, social relationships) that are each intended to measure an aspect of QOL. The number of items in each domain ranges from three to eight. An additional two general items are included (Jennes-Coussens et al., 2006). These are intended to measure overall QOL and general health. However, these two final items are not included in the overall scoring (Skevington et al., 2004). Each item is scored on a five-point Likert scale. Although it could be argued that the data collected from this scale should be classified as ordinal, Tabachnik and Fidel (2007) have indicated that measures using Likert scale items are often treated as interval data in the social sciences. Thus, for the purposes of this study data obtained from the WHOQOL-BREF was analyzed as interval data.

In a study conducted examining the psychometric properties of the WHOQOL-BREF, responses to each item were distributed across the range of possible answers and no indication of ceiling or floor effects for any of the items were present (Skevington et al., 2004). Each item was

found to contribute significantly to the variance of the test results (Skevington et al.). Internal consistency, measured by Cronbach alphas, ranged from 0.68 for the social relationships domain to 0.82 for physical health (Skevington et al.). Generally the acceptable range for these values includes any value greater than .70. However, considering the social relationships domain was based on only three items compared to the six to eight range for the other three domains, interpretation of the alpha value for this particular domain should be done with caution. Alpha values are sensitive to numbers and thus, a lower value for this domain was not unexpected considering the domain was only based on three items (Skevington et al.). Test-retest reliability scores for the WHOQOL-BREF ranged between 0.83 for the psychological domain to 0.86 for the physical domain (Melbourne WHOQOL Field Study Centre, 2000). The reading level for this measure is grade 5.1 (Jennes-Coussens et al, 2006).

Correlations between the WHOQOL-BREF and other QOL measures ranged from 0.04 for the social domain to 0.80 for the physical health domain (Melbourne WHOQOL Field Study Centre, 2000). However, the low correlation for the social domain with one of the measures can be explained by the fact that most of the measures used in this study were designed to measure only certain aspects of health-related QOL and thus, were not necessarily expected to correlate highly with all of the domains on the WHOQOL-BREF. For example, one of the measures used, the PCS index of the SF-36, was considered to be the gold-standard for the physical domain of the WHOQOL-BREF. Thus, it was expected that correlations between this measure and the physical domain of the WHOQOL-BREF would be adequate and indeed they were at .58. Similarly, a high correlation was found between the psychological domain and the gold-standard for this domain, the MCS index of the SF-36. The correlation between these two measures was found to be .70. While these correlations indicate evidence of construct validity for the physical

and psychological domains of the WHOQOL-BREF, no acceptable gold standard for the environmental and social relationships domains were used in this study. The .04 correlation found for the social domain of the WHOQOL-BREF then can be explained by the fact that this particular correlation was observed between the social domain and the PCS index of the SF-12, a measure intended to evaluate physical health only, with no social relationship component to it. Thus, it can be assumed that a low correlation would be expected from this comparison. The AQL was the only instrument used in this study with a social component to it. Not surprisingly, the correlation between this instrument and the social relationships domain of the WHOQOL-BREF was the highest of all comparisons with the social domain coming out at .48. However, it is important to emphasize that even this measure was not considered to be a gold-standard for the social relationships domain (Melbourne WHOQOL Field Study Centre, 2000).

Discriminative validity for the WHOQOL-BREF was measured through a comparison of the scores of sick and well participants. Significant discriminative validity was found for each domain, with the physical health domain demonstrating the greatest discriminative validity followed by the psychological, social, and environmental domains (Skevington et al., 2004). Angermeyer, Killian, and Matschinger (2001) also found that the WHOQOL-BREF adequately discriminates between individuals with and without somatic and psychiatric illness.

Concurrent validity was measured by correlating each domain score with each of the two additional items relating to overall QOL and health. The overall QOL item was most strongly associated with the psychological and environmental domains while the overall health item was most strongly correlated with the physical health domain. Furthermore, a combined score of the two additional items were shown to correlate strongly with all four domains. Skevington et al. (2004) have suggested that this result indicates that each of the four domains



contributes significantly to the variance in overall QOL and thus, each should be considered when measuring overall QOL. Results of the Skevington et al. study also showed that no item in the WHOQOL-BREF was associated more with any other domain than its own. Overall, the results of analyses of the internal consistency, concurrent validity, construct validity, and discriminant validity of the WHOQOL-BREF indicate good-to-excellent psychometric properties (Skevington et al.).

### *Statistical Analysis*

The current study was aimed at examining demographic and formal support variables and their relationships to quality of life scores. Descriptive analyses were completed for the questionnaire in order to provide details regarding current life circumstances of the participants. Each formal support variable included in the questionnaire as well as demographic information was then examined for significant correlations with each of the four QOL domain scores as well as the single-item QOL measure and an overall (composite) QOL score to determine whether any of the formal support variables or demographic variables examined significantly related to any aspects of QOL. The single-item QOL score was obtained from the, previously mentioned, overall QOL general item that is included as the first question in the WHOQOL-BREF. This question asks the participant “How would you rate your quality of life”. The participant then selects an answer based on a five point Likert scale. The overall or composite QOL score was calculated by averaging the scores on the four domains included in the measure. Standard regression analyses were also conducted using selected variables that were significantly correlated with QOL scores in order to determine which demographic and support variables can be used to predict QOL for the population being studied. A standard regression, as opposed to

statistical or hierarchical regression, was chosen as the most appropriate statistical procedure due to the exploratory nature of the study and the relatively small sample size employed.

### *Conclusion*

This chapter presented the methodology used for the current study. For this study, 389 members of AMI were contacted via email regarding participation. The final data was based on a total of 33 participants. Two instruments, a 48-item questionnaire modeled on one used in 2001 by the National Autistic Society in Britain, and the WHOQOL-BREF, were used to collect the data. The questionnaire went through minor modification to suit the needs of the study and questions were screened by board members of AMI prior to being used. The WHOQOL-BREF was shown to have good-to-excellent psychometric properties and was deemed to be adequate for use with this population. Demographic and formal support variables were correlated with QOL scores in the areas of Physical QOL, Social QOL, Environmental QOL, Psychological QOL, and Overall QOL and standard multiple regression analyses were employed to find suitable models to predict QOL scores.

## CHAPTER 4: RESULTS

### *Chapter Synopsis*

In this chapter the results of the study are reported. The chapter begins with a report of the descriptive statistics and is followed by an analysis of the inferential statistics. This chapter is followed by a Discussion chapter in which the results of the study are interpreted and the implications for the findings are examined.

### *Demographic Information*

Fifty six participants (8 women, 25 men) were recruited from a list of 389 members of AMI, giving a response rate of 14%. Of the 56 participants recruited 38 met the criteria for participation in the study. However, an additional four participants withdrew from the study prior to completing the survey leaving a total of 34 completed surveys. One additional survey was deleted after it was recognized that two surveys came from an identical IP address minutes apart. Upon further examination of the collected data from these entries, it was determined that the responses on the two completed surveys were identical and therefore, it was deemed highly likely that the responses came from the same individual. Therefore, one of the surveys was deleted leaving a total of 33 completed surveys.

Of the 33 participants who completed the survey, 12 indicated that at the time of the study they were between the ages of 18 and 24. A further 9 participants reported their age to be between 25 and 29, while 3 indicated that they were between the ages of 30 and 34. Two participants were between 35 and 39, and seven reported themselves to be over the age of 40. Twenty-seven of the participants who completed the survey reported that they are currently living in Winnipeg, while six noted their current residence to be somewhere in Manitoba but outside of Winnipeg.

### *Descriptive Statistics*

The following section describes the descriptive statistics that were obtained from the 48-item questionnaire. Information on the age, sex, and location of residence of the participants is included in this section as well as information on age of AS diagnosis, comorbid diagnoses, and reports of depression and anxiety. Statistics regarding objective outcomes are also included.

#### *Diagnoses*

Four questions in the survey were included that were related to the participants' AS diagnosis and comorbid diagnoses. In order to meet the criteria for participation in the study participants had to report that they received their diagnosis of AS from a qualified professional, such as a physician, psychiatrist, or psychologist, or a team that included at least one of those professionals. Of the 33 participants, 14 (42%) indicated that they received their diagnosis of AS from a psychiatrist, while 8 (24%) stated that their diagnosis was provided by a psychologist and 2 (6%) reported that they were diagnosed by a physician. A further 9 (27%) individuals reported that they were diagnosed by a team of qualified professionals.

Participants were also asked how old they were when they received their diagnosis of AS. In response to this question, only 3 (18%) participants indicated that they were diagnosed with AS before the age of 12. The most common response to this question was selected by 12 individuals (36%) who indicated that they were between the ages of 12 and 18 when they were diagnosed. A further 4 (12%) reported that they were between 19 and 24 when they received their diagnosis, while 9 (27%) indicated that they were older than 24 years of age. Two individuals (6%) stated that they did not know when they were diagnosed with AS. When asked about prior diagnoses 14 (42%) of the participants responded that they were diagnosed with something else before receiving their diagnosis of AS, while 11 (33%) indicated that they were

not and 8 (24%) indicated that they did not know. Table 1 summarizes the total number of participants who reported being diagnosed with other conditions prior to receiving a diagnosis of AS as well the total number of participants who had reported being diagnosed with other conditions in their lifetime.

Table 1

Comorbid Diagnoses

Diagnosis	Diagnosis Prior to AS	Lifetime Diagnoses
Depression	3	15
ADD or ADHD	8	9
Anxiety	3	17
Tourette's	1	1
ODD	0	1
OCD	2	5
Social Phobia	1	1

*Note:* Numbers in table represent the amount of participants to indicate each type of diagnosis they have received.

*Living Arrangements*

Two questions were used in the questionnaire to gather information regarding current living arrangements. Of the 33 participants 24 (73%) reported that they do not currently live alone, while the remaining 9 (27%) indicated that they are living on their own at the present time. In response to being asked where they are living, 16 (48%) participants reported that they live with their parents. A further 7 (21%) indicated that they are currently living in an apartment or house with drop-in support while 8 (24%) stated that they were living in an apartment or house without drop-in support. Another 2 participants selected the “other” option with one

indicating that they were currently living with their husband and the other stating that they resided in a “rooming house.”

### *Education and Employment*

Of the 33 individuals who participated in this study 27 (82%) responded that they graduated from high school while the remaining 6 (18%) indicated that they did not. Of those who did not graduate from high school, 5 individuals reported grade 11 as their highest grade completed and 1 individual stated that grade 10 was the highest completed. In response to being asked how they felt about leaving high school, 13 (39%) people indicated that they were excited or happy, 9 (27%) stated that they were unsure about how they felt, 5 (15%) reported that they felt anxious all the time, and 4 (12%) indicated that they felt anxious some of the time. Another 2 participants selected the “other” option which required further specification. In response to this one participant stated that they felt sad about leaving because it was the best time of their life while the other recorded that they felt extremely sad because it was “the end of daily interaction among peers”. Participants were also asked if they had taken any courses since leaving high school. In response to this 24 (73%) participants indicated that they had or are still taking courses, while 9 (27%) reported that they had not. Of the 33 people in the sample 16 (48%) noted that they had completed post-secondary degrees or certificates, while 15 (45%) individuals stated that they have not obtained a certificate or degree. A further 2 individuals did not record a response for this question.

Only 7 (21%) people in the sample reported that they currently had a paid full-time job, while 8 (24%) participants indicated that they had a paid part-time job. In contrast, the remaining 17 (52%) people who responded to this item stated that they were either not employed or were currently doing unpaid volunteer work. Another 2 individuals did not indicate their employment

status. Of the 21 participants who reported that they were engaged in some form of employment, paid or unpaid, only 7 (21% of the total sample) indicated that their work was related to some post-secondary training. Furthermore, of the 20 individuals who reported some form of employment (full-time paid, part-time paid, or volunteer), 3 (15%) responded by saying that they were completely satisfied with their jobs, while 7 (35%) reported being very satisfied. A further 7 (35%) indicated that they were somewhat satisfied with their jobs and 3 (15%) stated that they were not at all satisfied with their work. It is important to note that 3 participants neglected to respond to this question despite the fact that they did have the option to indicate that they were not currently employed.

### *Finances*

Participants were also asked two questions regarding their current financial situations. The first question asked from where participants received most of their money. In response to this question, 14 (42%) participants said that they received most of their money from paid employment. However, another 14 (42%) indicated that their money came mostly from the government, in the form of employment or income assistance or pension. A further 4 (12%) stated that most of their money is given to them by their parents, while 1 participant reported that they currently had no source of income.

When asked about financial assistance from their families, 11 (33%) individuals indicated that they receive financial support on a regular basis, while 13 (39%) stated that they do receive support but only on rare occasions. The remaining 9 (27%) reported that they do not receive any form of financial assistance from their parents.

### *Daily Living*

A series of questions was also posed to the participants regarding their need for assistance with some daily living activities. The question stated, “Do you need help to:” Table 2 summarizes the total number of participants who indicated “yes” and “no” for each daily living activity that was included in the questionnaire. Proportions for each response are also provided in the brackets behind the total number for each item. Only the one item regarding the need for assistance in dealing with letters or correspondence resulted in percentage of “yes” responses greater than 50%.

Table 2

#### Number of Participants Indicating Needed Assistance for Activities

Activity	Yes	No
Prepare a Meal	2 (6%)	31 (94%)
Do Housework	6 (18%)	27 (82%)
Pay Bills	9 (27%)	24 (73%)
Manage Money	8 (24%)	25 (76%)
Shop for Clothes, Groceries etc	6 (18%)	27 (82%)
Do Laundry	3 (9%)	30 (91%)
Deal with Letters or Correspondence (ie. from government or income tax)	21 (64%)	12 (36%)
Deal with Personal Care / Hygiene	2 (6%)	31 (94%)
Make Medical Appointments	9 (27%)	24 (73%)
Attend Medical Appointments	11 (33%)	22 (67%)

*Note:* The values in the two columns represent the amount of participants that indicated they did or did not need help for each of the activities listed.



### *Social Relationships*

Of the 33 participants who completed the questionnaire 24 (73%) indicated that they were single, while 5 (15%) reported that they were married and 4 (12%) noted that they were currently dating someone. However, it is interesting to note that 18 (55%) individuals in the sample did state that they had at some point been involved in a romantic relationship, while the remaining 15 (45%) reported that they had never had any romantic relations. In response to the question, “How easy do you find it to make friends?”, only 3 (9%) reported that they found it either “very easy” or “easy”. In contrast, 17 (52%) individuals indicated that they found it either “hard” or “very hard” to make friends, while 9 (27%) stated that they found it “neither easy nor hard”. A further 4 (12%) decided to chose the response that stated “I don't have any friends.”

Participants were also asked to select an appropriate response to the question, “How satisfied are you with your current friendships?” For this question 20 (61%) of the participants indicated that they were either “very satisfied” or “somewhat satisfied”, while 10 (30%) reported being either “dissatisfied” or “very dissatisfied”. The remaining 3 (9%) participants chose the option that stated “I am neither satisfied nor dissatisfied”. In response to being asked whether the participants had a best friend, 13 (39%) reported that they did not, while 20 (61%) stated that they had either one best friend or more than one best friend.

In response to the question “How would you rate your social life?” 12 (36%) participants chose the option that read “extremely poor (or far worse than the average person)”. A further 16 (48%) reported that they believed their social lives were “in between extremely poor and average”, while only 3 (9%) rated their social lives as “average”, and only 2 (6%) reported them to be “in between average and excellent” or “excellent”.

### *Incidents with the Law*

Three questions were included in the questionnaire to help gain insight into the extent to which difficulties with the law may occur in the lives of adults with AS. According to the responses provided by the participants, 10 individuals (30% of the sample) have, since the age of 18, been the victim of a crime. On the other hand, 2 (6%) of the participants who responded reported that they had been charged with a crime since the age of 18. However, the same proportion of participants also indicated that they had been charged with a crime that they did not commit.

### *Physical Health Concerns*

Four questions were included in the questionnaire regarding physical health concerns. According to the answers provided, 7 (22%) individuals in the sample have been diagnosed with a serious physical health condition. Included in the health concerns specified by the participants were: hypertension, obesity, Chron's disease, rheumatoid arthritis, pancreatitis, and two cases of diabetes. One individual specified their physical health concern to be depression along with one case of drug induced psychosis. However, for the purposes of this study this specific concern has been treated as a mental health concern rather than a physical health concern, thus, bringing the total proportion of participants with serious physical health concerns to 19% of the total sample. It is interesting to note that 1 individual did not provide a response for this question.

To follow up on the initial question regarding physical health, a second question asking “Do you have any physical health problems that are making it difficult to carry out your daily activities?” was included. The responses indicated that 6 (18%) individuals in the sample did believe that they had a physical health problem that was seriously affecting their daily lives. Included in the specified responses were: one individual who indicated that both their

hypertension and obesity were affecting them, one report of a genetic abnormality in the individual's development of their adult teeth that has severely affected their ability to socialize, one individual who reported that they were blind, one report of dysplasia of the knee as well as glaucoma, an individual who cited being overweight, and one case of psoriasis.

In order to obtain more information on physical health concerns, participants were also asked whether they experience any chronic pain. In response to this question 7 (21%) participants stated that they did have some sort of chronic pain. However, it is important to note that 1 of the individuals who reported chronic pain specified it to be “intermittent numbness of the soul/mind (with) lethargy/boredom”. While it is important to acknowledge this response, the question was aimed at determining the proportion of the sample suffering from chronic physical pain and therefore, this response has not been included from the response count, making the total proportion of individuals in the sample reporting chronic pain to be 18%. Included in the specified responses regarding chronic pain were: one individual who reported back and knee pain, another who noted headaches and joint pain, another who simply stated “knee”, one report of arthritis in both the knee and neck, another report of assorted work injuries, and one individual who stated that their “stomach always hurts”. When asked if there were any physical health problems that the participants felt were not adequately treated, 4 (12%) responded with a “yes”, while the remaining 29 (88%) stated that they did not.

#### *Mental Health Concerns (Anxiety and Depression)*

Two questions were included in the questionnaire that dealt with specific mental health concerns. In response to the question, “How often do you feel depressed?” 11 (33%) participants in the sample reported either that they never felt depressed or that they rarely felt depressed. An additional 12 (36%) indicated that they felt depressed some of the time or at least once a month,

while the remaining 10 (30%) were split between individuals reporting that they often felt depressed (at least once a week) and individuals reporting that they always felt depressed (several times a day).

In response to the question, “How often do you feel anxious?” 9 (27%) individuals stated that they either never felt anxious or rarely felt anxious. The response “sometimes” was selected by 12 (36%) individuals while an additional 5 (15%) reported that they often felt anxious (at least once a week). A further 7 (21%) indicated that they always felt anxious.

### *The Need for Support*

A series of eight questions regarding the need for assistance were included in the questionnaire to describe how inadequate support may be affecting the QOL of participants surveyed. Table 3 summarizes the number of participants in the sample that answered “yes” or “no” to each of the questions. The proportion of the sample that agreed or disagreed to each statement is also provided in the brackets beside each total.

### *Formal Supports*

Several questions were included in the questionnaire in order to help in determining the extent to which formal supports are available and accessed by this population. One major formal support that was of interest in the study was the presence of transition planning, a formal support sometimes offered by school that is intended to help prepare individuals for life after high school. In regards to this support, only 10 (30%) participants reported that they were involved in the creation of a transition plan whereas 21 (64%) indicated that they did not have any type of transition planning in place. The remaining 2 (6%) stated that they did not know whether they were provided with the opportunity to create a transition plan with school staff.

Table 3

## Number of Participants Agreeing or Disagreeing with Support Statements

Statement	Agreed	Disagreed
With more support I would be able to live more independently.	18 (55%)	10 (30%)
With more assistance I think I would be able to work more.	17 (52%)	8 (24%)
With more assistance I think I would feel less isolated.	15 (45%)	7 (21%)
With more assistance I would be more able to do the things I want to do.	14 (42%)	7 (21%)
With more assistance I think my general health would improve.	14 (42%)	10 (30%)
I have experienced anxiety because of a lack of assistance.	18 (55%)	9 (27%)
I have experienced depression because of a lack of assistance.	14 (42%)	12 (36%)
I have experienced severe mental health difficulties because of a lack of assistance.	7 (21%)	18 (55%)

*Note:* Proportions were based on “Agree” and “Disagree” answers only. Missing proportion can be accounted for by participants selecting “I neither agree nor disagree”.

Participants were also asked whether they currently had a social worker, community health worker, or case manager currently working with them. In response to this question, 13 (41%) reported that they did currently have someone working with them, while 17 (53%) indicated that they did not. Another 2 (6%) stated that they did not know if someone was working with them and 1 individual did not provide an answer for the question. In regards to whether participants were currently receiving support or services from a government or non-governmental agency, 18 (55%) indicated that they were with 11 (33%) reporting accessing

support or services from a government agency and 7 (21%) accessing from a non-governmental agency. A further 14 (42%) indicated that they were not accessing any agency support or services, while 1 individual stated that they did not know if they were.

One question included in the questionnaire provided a checklist to participants to allow them to indicate other formal supports that they were currently accessing. Table 4 summarizes the number of participants (as well as the corresponding proportions) who reported that they were, at the time of the study, accessing each type of formal support.

Table 4

Number of Participants Accessing Different Types of Formal Support

Support	Proportion Accessing
Social Groups	7 (21%)
Employment Support	11 (33%)
Counselling or Psychotherapy	14 (42%)
Educational Support	3 (9%)
Psychiatry	10 (30%)
Physiotherapy	1 (3%)
Advocacy	5 (15%)
Social Skills Training	3 (9%)
Daily Living Support	5 (15%)
Occupational Therapy	2 (6%)
Peer Support Groups	9 (27%)
None	6 (18%)

In addition to the checklist provided for indicating which supports were currently being accessed, another checklist was included for participants to select which formal supports, if any, that they were not receiving did they think would be beneficial to them. The results of this question are summarized in Table 5. The table shows the number of participants who believed that they would benefit from each type of support that they were not currently receiving. The proportions included beside each total represent the percentage of individuals who are not receiving each type of support who felt that they would benefit from that support.

Table 5

## Number of Participants Indicating They Would Benefit From Supports

Support	Proportion Indicating They Would Benefit
Social Groups	12 (46%)
Employment Support	8 (36%)
Counselling or Psychotherapy	6 (32%)
Educational Support	7 (23%)
Psychiatry	1 (4%)
Physiotherapy	1 (3%)
Advocacy	6 (21%)
Social Skills Training	11 (37%)
Daily Living Support	3 (11%)
Occupational Therapy	4 (13%)
Peer Support Groups	9 (38%)

*Note:* Proportions are based on the total number of participants who were not receiving each specific support.

It is important to note that on the question regarding supports that have not been accessed but may be of some benefit, four participants selected the “other” option. For this option participants were asked to specify what other supports they believe they would benefit. In response to this, one individual simply indicated that they would like to be employed, while another stated that they believe they would benefit from government employment funding. One individual simply stated “proctor” without any further explanation, while another stated that they were unsure about what physiotherapy was but that if they knew more about it they may have selected it as a support that would be of benefit to them.

Participants were also provided with a question in which they were asked if they believed they had enough assistance or services to meet their needs. In response to this, 12 (36%) reported that they did, while 8 (24%) indicated that they believed they did not. The remaining 13 (39%) stated that they did not know whether they received enough assistance or services to meet their needs.

### *Statistical Analysis*

This section explains how the data was analyzed. It includes information regarding the steps that were taken to ensure that the data was entered properly as well details surrounding missing data. The steps that were taken to ensure that the assumptions for the analyses were met were also included. This section is concluded with a description of the significant statistical findings.

### *Data Screening*

After the initial data was entered, the data was checked over twice for incorrect values. Incorrect data, was then subsequently, reentered to reflect the correct values.



### *Missing Data*

Some data were missing from the questionnaire because specific items had not been completed by the participants. As part of the informed consent, participants were free to neglect completing any portion of the questionnaire. As a result, information regarding the missing data or the reasons for not completing specific items was not pursued by the researcher. However, it is important to note that in total, only three individual pieces of data were missing, two of which came from the same individual, both items dealing with age of diagnosis. Considering, participants were given the option of choosing “I don’t know” to answer these two items, it is difficult to determine why exactly the items were not completed. Apart from this, only one other question from one participant was not completed. This item was in reference to whether the participant currently had a social worker, community health worker, or case manager working with them. Once again the reason for the missing data is unknown as participants were also given the option of reporting “I don’t know” for this item. Tabachnik and Fidell (2007) indicated that both the pattern and amount of missing data should be considered when making decisions regarding what to do with missing data. However, they have also pointed out that, to date, there are no specific guidelines for decision making when it comes to how much missing data is acceptable for varying sample sizes. They have though, stated that if only a few cases have missing data and they seem to be random, deletion is an acceptable approach. Considering the small amount of missing data and the lack of any recognizable pattern within the missing data, it was decided that the best option would be to continue analysis while simply deleting cases with missing values.

### *Distributions*

Distributions were examined for normality as well as the presence of outliers. For the continuous variables employed in the study raw scores were transformed to z-scores to search for the presence of outliers. According to Tabachnick and Fidell (2007), scores in excess of 3.29 can be considered potential outliers. Using this criterion, no outliers were found in any of the interval data. The dichotomous variables used in this study were also examined for outliers. However, Tabachnick and Fidell have pointed out that when examining dichotomous variables for outliers it is cases on the “wrong side of a very uneven split that are likely univariate outliers” (p. 73). According to Rummel (1970), dichotomous variables with splits of 90-10 or more should be deleted because correlations with these variables and others will likely be too highly influenced by the category with fewer cases. Two dichotomous variables used in this study, accessing of physiotherapy and accessing of occupational therapy, fit the criteria of a 90-10 or greater split. Thus, in accordance with Rummel's suggestion these variables were excluded from further analysis.

To determine whether the continuous variables used in the study were distributed normally, the skewness and kurtosis of each distribution was examined. According to Tabachnick and Fidell (2007), skewness represents the symmetry of a distribution, while kurtosis is a measure of its peakedness. When a distribution is normal, skewness and kurtosis values will be zero. However, it is important to note that when evaluating deviations from normality alpha levels of .01 or .001 can be used for small to moderately sized samples (Tabachnik & Fidell; Field, 2005). Z- scores in excess of  $\pm 2.58$  indicate a significance level greater than .01. According to this criterion, all skewness and kurtosis values measured for this study meet acceptable standards for normality. Skewness and kurtosis values for each of the distributions

used in the study are presented in Table 6, with z-scores included in brackets behind the raw score value for each distribution.

Table 6

Skewness and Kurtosis Values for Distributions

Distribution	Skewness Value	Kurtosis Value
Physical QOL	-.267 (-.65)	-.958 (-1.21)
Psychological QOL	-.373 (-.91)	-.403 (-.51)
Social QOL	.160 (.39)	-.629 (-.78)
Environmental QOL	-.888 (-2.17)	.773 (.97)
Composite QOL	-.332 (-.81)	-.111 (-.14)
Single Item QOL	-.666 (-1.63)	.592 (.74)
Help w/ Daily Activities	.510 (1.25)	-.930 (-1.17)
Total Supports	.818 (2.00)	.295 (.37)

*Note:* Z-scores are in parenthesis beside the raw score. Z-scores in excess of  $\pm 2.58$  indicate a significance level greater than .01. No values examined were significant at .01, thus, indicating adequate normality for all distributions.

A visual examination of residual scatter plots measuring predicted values against residuals was also conducted in order to determine whether the assumptions of normality, linearity, and homoscedasticity of residuals were met for each of the multiple regression models tested (Tabachnik & Fidell, 2007). According to the residual scatter plots, all regression models met the assumptions of normality of residuals, linearity, and homoscedasticity.

### *Correlations*

Pearson's correlations and point-biserial correlations were conducted to measure the relationships between demographic information, formal support variables, and measures of QOL. According to Cohen (1988), a correlation of 0.5 is large, 0.3 is moderate, and 0.1 is small. A series of bivariate analyses revealed significant moderate associations between demographic variables and Social QOL as measured by the WHOQOL-BREF. The analyses found that individuals who were female had a significantly higher Social QOL than those who were male ( $r(31) = .314, p = .038$ ), while participants who were married also reported a higher Social QOL ( $r(31) = .335, p = .028$ ) than those who were not. In addition, Social QOL scores were also reported to be higher for individuals who indicated that they were currently living in Winnipeg as opposed to areas in Manitoba outside of Winnipeg ( $r(31) = -.359, p = .020$ ). A significant moderate correlation was also observed between the age of diagnosis and the single-item QOL score, in that individuals diagnosed prior to the age of 19 tended to score higher than those diagnosed later in life ( $r(30) = -.314, p = .040$ ).

With regards to formal support factors, participants were asked a series of questions concerning whether they were currently accessing 15 different types of formal support. Types of support measured in this study were: Secondary education to graduation transition plans, the accessing of government or non-governmental support agencies, the use of a social worker, community health worker, or case manager, social groups, employment support, counselling or psychotherapy, educational support, psychiatry, physiotherapy, advocacy, social skills training, daily living support, occupational therapy, and peer support groups. While six of the fifteen formal support factors were found to be significantly related to QOL scores, two of the variables, physiotherapy and occupational therapy, were deleted due the fact that they did not meet the

criteria for normality for dichotomous variables. In regards to the other four variables, it was observed that individuals who were currently accessing a psychiatrist reported lower Social QOL scores ( $r(31) = -.329, p = .031$ ), while individuals accessing counselling or psychotherapy indicated a lower single-item QOL score ( $r(31) = -.366, p = .018$ ). In addition, two formal support variables were found to be significantly associated with Environmental QOL. The results showed that individuals who were accessing a social worker, community health worker, or case manager had lower reported Environmental QOL scores ( $r(30) = -.334, p = .031$ ) and those who were involved in social groups also indicated their Environmental QOL to be lower ( $r(31) = -.425, p = .007$ ).

Participants were also asked to complete a checklist on the questionnaire that was aimed at determining the amount of support needed for daily living activities. Ten items were listed in this question in which the participant was asked “Do you need help to...?” For each item participants were provided with the option of answering “yes” or “no.” The total “yes” answers for each participant were then combined to form the total help variable. The results of the analyses indicated significant relationships with a number of other variables. It was observed that the more help participants needed with daily activities the more likely they were to be accessing a social worker, community health worker, or case manager ( $r(30) = -.355, p = .023$ ), employment support ( $r(31) = -.312, p = .038$ ), counselling or psychotherapy ( $r(31) = .312, p = .038$ ), and daily living support ( $r(31) = .291, p = .05$ ). Furthermore, it was also observed that the more help the participants reported needing, the lower their scores were in the areas of Physical QOL ( $r(31) = -.507, p = .003$ ), Social QOL ( $r(31) = -.421, p = .015$ ), Environmental QOL ( $r(31) = -.436, p = .011$ ), and Overall QOL ( $r(31) = -.504, p = .003$ ). Total help was also

significantly associated with the total time it took to complete the survey ( $r(31) = .385, p = .027$ ) and the total amount of support accessed ( $r(31) = .434, p = .012$ ).

In addition to being significantly associated with total help, the total supports accessed variable was also found to be significantly correlated with two other variables. Analyses found that individuals who were, at the time of the study, currently employed or in school accessed less total supports than those who were not ( $r(31) = -.548, p < .001$ ). In addition those who reported accessing more total supports also scored lower in the area of Environmental QOL ( $r(31) = -.385, p = .027$ ).

### *Regression Analyses*

Standard multiple regression analyses were conducted to determine whether the measured demographic and support variables would explain a significant amount of variance in QOL scores. Table 7 summarizes the results of the regression analyses, including the amount of variance accounted for and the significance levels for each model. According to Tabachnik and Fidel (2007), the  $R^2$  value tends to somewhat overestimate the regression model. This, they suggest, can be more pronounced when smaller sample sizes are employed. Therefore, an adjusted  $R^2$  value has been calculated to take into account the number of predictor variables used in the model as well as the number of participants on which the model is based. In essence, this adjusted  $R^2$  value represents a more conservative estimate of the success of the model. For this reason, both the  $R^2$  value and the adjusted  $R^2$  value have been reported.

The first regression analysis conducted was completed using three variables to predict Environmental QOL. While four of the measured variables were found to be significantly correlated with Environmental QOL, only the three with the largest correlations were used in the model to ensure the ratio of independent variables to cases did not grossly overestimated the

result (Tabachnik & Fidell, 2007). Variables used in the model were: social groups, help with daily activities, and total supports. The three variables together accounted for 37% of the variance in Environmental QOL scores (30% adjusted:  $F(3,29) = 5.619, p < .005$ ). A total of five variables were found to significantly relate to Social QOL. However, only the three with the largest correlations were used in the model: location of residence, marital status, and help with daily activities. Once again this was done to limit the number of independent variables used in the model. These three variables were found to predict Social QOL with 33% of the variance accounted for (26% adjusted:  $F(3,29) = 4.70, p < .01$ ). An additional regression analysis was conducted using three variables that were significantly correlated with the total numbers of supports being accessed: help with daily activities, employment or enrolled in educational program, and Environmental QOL. The regression analysis using these variables accounted for 49% of the variance in overall supports accessed (43% adjusted:  $F(3,39) = 9.146, p < .001$ ).

Table 7

## Multiple Correlation Values for Three Regression Models

Model	R <sup>2</sup>	Significance
Social QOL:	0.327	< .01
Relationship, Location, Help		
Environmental QOL:	0.368	< .005
Social Groups, Total Supports, Help		
Total Supports:	0.486	< .001
School or Job, Environmental QOL, Help		

### *Conclusion*

The results of the data analysis showed four significant correlations between specific formal supports and QOL scores. The hypothesis at the outset of the study was that there would be at least some positive correlations between formal supports and QOL scores. However, each of the significant correlations found between formal supports and QOL scores were negative, indicating that individuals who accessed those formal supports were more likely to have lower scores on the corresponding QOL measures. Only one variable, help with daily activities, correlated significantly with the overall QOL score. This variable also correlated significantly with Physical QOL, Social QOL, and Environmental QOL. That is, individuals who reported needing more help with their daily activities were more likely to report lower scores on each of these QOL measures. Three significant regression models were also included. These models were able to predict 33% of the variance in Social QOL, 37% of the variance in Environmental QOL, and 49% of the variance in the total amount of supports accessed by the participants.



## CHAPTER 5: DISCUSSION

### *Chapter Synopsis*

This chapter begins with a description of the results and the implications of the findings. This is followed by a discussion regarding the limitations of the current study and finally by a section dedicated toward recommendations and suggestions for future research.

### *Findings*

The present study is, to the researcher's knowledge, the first study to explicitly explore the relationship of multiple specific formal support variables to QOL for individuals with AS. While the study was exploratory in nature, it was hypothesized that the accessing of at least some formal supports would be significantly positively correlated with QOL scores.

An exploration of the descriptive statistics calculated from the 48-item questionnaire showed a number of issues related to QOL that are cause for concern. Of the 33 participants who completed the survey, only 3 (18%) reported being diagnosed with AS prior to the age of 12. The most common response to this question was between the ages of 12 and 18, chosen by 12 (36%) people. These results, at first glance, appear to be concerning considering the fact that research has found that early interventions for children with developmental disabilities can be extremely beneficial in terms of cognitive abilities, linguistic abilities, social skills, and self-help skills (Rogers, 1996; Dawson & Osterling, 1997 as cited in Howlin & Asgharian, 1999) and that higher levels of satisfaction with school have been reported by parents when diagnoses were in place earlier (Barnard, Harvey, Potter, & Prior, 2001). Furthermore, Howlin and Asgharian have pointed out that later diagnoses can result in negative outcomes when children are not provided with the educational support and accommodations that they need and that academic failures can often result in depression, low self-esteem, and rejection by peers (Howlin, 1988 as cited in

Howlin & Asgharian). However, it is important to note that the sample used for this study was taken from a pool of adults, some of which reported that they were over the age of 40. Therefore, the small proportion of individuals reporting receiving a diagnosis prior to the age of 12 could be attributed to the more recent recognition of AS, rather than any current trends in diagnoses. That is, it is highly likely that the late age of diagnoses reported in this sample is simply a result of the fact that AS was very rarely diagnosed when a lot of the participants would have been under the age of 12. Therefore, the results found within this sample, in terms of age of diagnoses, cannot necessarily be generalized to the more current trends in AS diagnoses.

It is interesting to note that many of the individuals surveyed for this study reported being diagnosed with something prior to receiving their AS diagnosis, a fact that may suggest a lack of awareness of the signs and symptoms of AS amongst the professionals who made the initial diagnoses. However, once again this may be more representative of the lack of awareness of AS in the past several decades rather than the current state in the field. Regardless, it is quite possible that the delays in diagnoses amongst the participants of this study may have had some negative effects. However, according to the results of the current study, the only indicator of any relationship between age of diagnosis and QOL was observed by a moderate correlation that indicated that individuals diagnosed prior to the age of 19 scored higher on the single-item QOL score. Considering no other QOL scores were significantly correlated with age of diagnosis, it is difficult to conclude anything on these findings.

Of particular importance is the fact that there are a number of comorbid conditions that appear to have been extremely prevalent in the sample. For instance, 17 (52%) individuals indicated that they had at some point in their lives been diagnosed with some type of anxiety disorder, while 15 (45%) indicated that they have received a diagnosis of depression, and 9

(27%) ADHD. According to Ghaziuddin, Weidmer-Mikhail, and Ghaziuddin (1998), these types of findings are common in this population, with depression being the most common comorbid condition for adolescents and adults, and ADHD the most common for children. Ghaziuddin et al. have also reported anxiety disorder and bipolar disorder to be common comorbid conditions in AS. However, it is still uncertain whether some of these disorders, such as depression and anxiety, are purely a result of biological factors that are linked to AS or the result of difficulties coping and the social stigmas that are attached to the symptoms of AS (Ghaziuddin et al.). Regardless, it is important to acknowledge that these issues need to be addressed adequately within this population in order to improve their overall QOL.

The vast majority of the individuals who participated in this study reported that they had graduated from high school, while over half indicated that they had obtained post-secondary degrees or certificates. An additional 8 (24% of the total sample) reported that they had taken post-secondary classes but had not yet finished their programs. However, over half of the participants stated that they were either not employed or were currently doing unpaid volunteer work and 14 (42%) individuals indicated that their money came mostly from the government, in the form of employment or income assistance. Not surprisingly then, almost half of the participants surveyed indicated that they were currently living with their parents. According to Barnhill (2007), underemployment in this population is a common problem that is likely due to the fact that their difficulties in the areas of social skills usually make it challenging to engage appropriately in the type of interaction required in job interviews. Barnhill also suggests that deficits in social skills can lead to immediate loss of employment, a situation that can sometimes result in a great deal of pain and embarrassment. Good, Rutter, and Howlin (1994 as cited in Barnhill, 2007) have suggested that because individuals with AS are more able than those with

more severe autism spectrum disorders, they may be more distressed by their difficulties navigating through the social world, an issue that could potentially lead to a cycle of mental health difficulties and further unemployment.

Considering the findings of the current study as well as numerous others, it is not surprising that employment support was found to be one of the most accessed formal supports studied. However, despite this fact, only 11 (33%) participants indicated that they had accessed employment support, a result that is staggering when one considers the findings reported by Mawhood and Howlin (1999), that individuals with HFA and AS receiving employment support are more likely to be employed, more likely to find higher level jobs, more likely to work for a greater percentage of time, and more likely to receive higher wages. Given these findings, it is difficult to understand why more adults with AS are not accessing some form of employment support. However, what was found from this study was that 8 of the 22 individuals (36%) who were not receiving employment support indicated that they believed they would benefit from it. Considering these results, it could be beneficial for future research to employ qualitative methods to gain a more thorough understanding as to whether these supports have been offered and why or why not they are being accessed.

According to Howlin (2000), it is difficult to find documented evidence of an excess of criminal activity involving individuals with AS. However, Barnhill (2007) suggested that due to a number of factors, including the challenges in reading people and interpreting subtle social cues, individuals with AS may be more susceptible to being set up by others to be accomplices in crimes or unlawful activities. According to the results of this study only 2 (6%) of the participants have been charged with a crime and in each instance the individual stated that they were charged for a crime that they did not commit. Whether this is evidence to support Barnhill's

assumption is not clear and any conclusions from this information are not possible without further information. However, what is of particular interest is that 10 (30%) of the participants reported that they have, at some point in their lives, been a victim to a crime. The details of these crimes, though, were not collected, indicating that these results should be interpreted with extreme caution.

In a study conducted comparing WHOQOL-BREF scores of adults with AS to a control sample, Jennes-Coussens, Magill-Evans, & Koning (2006) found that individuals with AS scored lower on both the social and physical QOL domains. However, it is important to note that sample size used in the Jennes-Coussens et al. study were extremely small. To further investigate the findings produced by this study in the area of Physical QOL, four questions were included in the current study to gain insight into the physical health concerns that are affecting individuals with AS. Considering the recent research that has found that many individuals on the autism spectrum suffer from chronic abdominal pain due to abnormalities of the gastrointestinal system (MacFabe et al., 2007) it was expected that complaints of abdominal pain would be common. However, only one individual in this study reported any issues with the gastrointestinal system. No other recurring problems were evident from the responses provided by the participants.

In regards to social relationships, 24 (73%) of the 33 participants indicated that they were currently single, while 15 (45%) reported that they had never been involved in a romantic relationship. Considering the moderate correlation found in this study between relationship status and Social QOL, in favour of those who reported being married, it is important to acknowledge that in most studies that have looked at the social relationships of adults with AS, the vast majority of participants have been single (Howlin, 2000). However, it is also important to acknowledge the fact that the correlation found in this study in no way indicates a causal

relationship. In fact, it is possible that being married does not, in any way cause one's Social QOL to increase but rather that those who report a higher Social QOL may in fact do so because they have better developed social skills, which in turn, allow them to be more successful in initiating and maintaining romantic relationships. In order to determine exactly what the relationship is between these two variables, further research will need to be conducted in this area.

It is also important, when analyzing the descriptive statistics regarding social relationships, to acknowledge the fact that 17 (52%) of the participants in this study indicated that they found it either “hard” or “very hard” to make friends and that the vast majority of participants rated their social lives either to be “extremely poor” or “in between extremely poor and average.” However, only 3 (9%) individuals indicated that they were receiving any social skills training, while 11 of the 30 (37%) individuals who were not receiving any believed they would benefit from it. Given these findings as well as similar ones presented in past research (Howlin, 2000), and the possible link between social skills and employment success, it is imperative that social skills training be offered to all individuals with AS and that governments be aware of the dire need for this type of service.

It is also interesting to note the moderate correlation found in this study in regards to location of residence and Social QOL. The results of this study found that individuals who lived in Winnipeg, the major centre in Manitoba, as opposed to anywhere else in Manitoba, reported their Social QOL to be higher. While it is important to acknowledge that this correlation, in no way implies a causal relationship, it could lead one to believe that there may possibly be services lacking in areas outside of Winnipeg, the major metropolis in Manitoba, that are in some way connected to Social QOL scores. However, it could also be implied that sheer differences in

population density could play a role. Regardless, at this point all that can be said about these two variables is that there appears to be a relationship in the sample used in this study. In order to determine if indeed there is something about location of residence that affects Social QOL, more research will need to be completed. However, these preliminary findings should be of interest to AMI considering their mandate is to provide services to all adults with AS in Manitoba.

One other variable, help with daily activities, was also found to be moderately correlated with Social QOL. That is, those who indicated that they needed more help with their daily living activities reported lower Social QOL scores. However, it is important to note that the help with daily activities variable was also significantly negatively correlated with Physical QOL, Environmental QOL, and Overall QOL, and was positively correlated with the total time it took to complete the survey. However, it is important to note that although cognitive abilities may appear to be a possible underlying factor that could explain these relationships, it has been found that variation in intelligence in high-functioning individuals on the autism spectrum does not have predictive value in terms of outcomes (Howlin, 2004). Whether, it has any predictive value in terms QOL remains to be determined. However, what these results may do is provide evidence that there are relationships between QOL scores and practical life skills, a finding that would suggest more emphasis be placed on the teaching of practical life skills prior to adulthood. However, without further research it is difficult to make any conclusions on this matter. Further research in this area should be dedicated toward determining whether there is any type of causal relationship at play between these variables.

The help with daily activities variable was measured using a 10-item question that asked: “Do you need help to:” followed by a series of daily activities. While none of the items were completely agreed upon by the participants, the results of several of the items are of particular

interest. Of most interest is the item that asked whether the participants needed help to deal with letters of correspondence, such as those that would be sent by government offices. On this specific item an overwhelming 21 (64%) participants indicated that they did need help. No other item on this question reached a proportion greater than 50%, but several items such as attend medical appointments, make medical appointments, pay bills, and manage money should be noted when addressing common areas in which this population may need assistance.

Another question was provided in order to gain information on how the participants believe they would benefit if they were provided with more support and how they may have suffered in the past because of a lack of support. In response to this question over half of the participants reported that they believed they would be able to live more independently and work more with more support and over half of the sample also reported that they believed they had experienced anxiety because of a lack of support. A further 15 (45%) individuals indicated that they would feel less isolated with more support, that they would be able to do more of things they wanted with more support, and that their general health would improve with more support. Another 14 (42%) of the participants also reported that they have experienced depression from a lack of support.

The most accessed supports measured in this study were found to be counselling or psychotherapy with 14 individuals (42%), employment support with 11 (33%), and psychiatry with 10 (30%). In regards to support factors, it was expected that at least some of the formal supports would be positively correlated with QOL scores. This hypothesis was based on the assumption that at least some formal supports would improve QOL for adults with AS. However, the results of this study showed no positive correlations between any of the formal support variables and QOL scores. On the contrary, four formal support factors were found to be



significantly negatively correlated with various aspects of QOL. The results revealed that individuals seeing a psychiatrist reported a lower Social QOL score than those who were not, while individuals accessing counselling or psychotherapy reported a lower single-item QOL score than those who were not. Furthermore, individuals who had either, a social worker, community health worker, or case manager working with them or attended social groups reported lower Environmental QOL scores. While these findings may, at first glance, appear to be contrary to what one might expect, it is important to consider that each of these services may be sought out by individuals with lower QOL scores in an attempt to improve aspects of their lives with which they are not satisfied. Thus, despite the fact that the results fail to provide evidence to support the need for these specific supports, further research may in fact find that these supports do improve QOL scores over time for individuals with AS. However, the results of this study show no evidence that the formal supports measured improve QOL for this population. Until further research is conducted to explore causal relationships, all that can be said is that there does appear to be a negative relationship between some formal supports and specific QOL scores.

In order to help determine the combined effect of the accessing of formal supports, the total amount of supports accessed by each participant was added up to form the total supports variable. Although very few of the individual support variables were found to significantly correlate with QOL scores and none were found to positively correlate with QOL scores, the total support variable was found to correlate significantly with three other variables. A significant negative correlation was found between the number of total supports and Environmental QOL. That is, individuals who reported accessing more supports were more likely to score lower in the Environmental domain, a category characterized by satisfaction with finances, transportation,

housing, access to information, and health care. A significant positive correlation was found between the number of total supports accessed and the number of daily activities with which the participants indicated they needed help. A further significant correlation was found that showed that individuals who either had a job or were currently in school, were less likely to access as many supports as those who were not employed or in school. Together, these three variables were able to predict 49% of the variance in the total amount of support accessed.

While it is difficult to assess from these results exactly why these variables were predictive of the amount of total supports accessed, there are some obvious possible explanations that could account for these findings. For example, it could be possible that people who are in need of more support are simply accessing more support. Those people who indicated that they need more help with their daily activities then would likely access more support because they need to in order to cope, while those individuals who are not employed or in school are accessing more support due to the fact that they either have more time to access supports or that they recognize they are in need of some sort of help because there is something that is hindering them from being productive. Considering the Environmental QOL score was correlated significantly with more support variables than any other QOL score, it is not surprising that it was correlated more strongly with the total supports accessed than any other QOL score. However, in terms of Environmental QOL, what is important to recognize is that there is something about low scores in that domain that make it more likely for individuals to access specific supports, such as social workers and social groups. What exactly that is at this point can only be speculated. What may be of most importance with this particular finding is that almost half of the variance in total supports accessed can be accounted for by three variables. Considering the amount of money that governments spend to provide these supports, it may be beneficial to continue the research in

these areas to determine why these specific variables are able to predict the total supports accessed. Furthermore, it may also be valuable for future research to determine whether there is an underlying variable that has not been measured in this study that is related to all three independent variables and whether anything can be done to influence the amount of supports being accessed by this population.

### *Limitations*

In evaluating the findings of this study, it is important to acknowledge the fact that the responses provided by the participants were, for the most part, subjective perceptions of their own well-being and the services that they have or have not received. While the current literature in the area of QOL suggests the need for a more subjective way of measuring QOL, there were a number of qualitative observations made during the data analysis stage of this study that called into question the ability of this type of measure to accurately assess QOL for this population. For instance, when asked in the WHOQOL-BREF survey about their satisfaction with their personal relationships, a number of individuals answered this question with very positive responses despite the fact that they had responded more negatively to previous questions in the questionnaire regarding how easy they found it to make friends and whether they had ever been in a romantic relationship. Although it could be possible that an individual has never been involved in a romantic relationship and finds it difficult to make friends but at the same time is satisfied with the current relationships they have, this pattern was observed several times, casting some doubt on whether some individuals in the sample were able to accurately reflect on some aspects of their lives or were willing to be honest about their perceptions. However, considering the fact that research has found that objective measures of outcome do not always correlate very well with subjective well-being (Cummins, 2000), it is possible that the responses provided by

the participants in this study were an accurate reflection of their subjective impressions of their QOL. At this point, though, there is no way to assess the accuracy of the responses provided and therefore, they must be taken at face value.

It is also important to acknowledge the fact that the data used in this study was based on a number of assumption. First of all, it was assumed that the individuals from whom the data was collected were indeed adults with a diagnosis of AS who were, at the time of the study, residing in Manitoba. Considering there was nothing in place to monitor whether the participants were who they said they were, this could be considered a major limitation to this study. Secondly, the data collected for this study was based on the assumption that those individuals who participated in the study had a vested interest in answering honestly to all items on the questionnaire and survey. It could, therefore, be considered a major limitation to this study that none of the information provided by the participants could be verified. Finally, although there was one question in the questionnaire that asked if the participants received their diagnosis from a qualified professional, it is possible that even qualified professionals would differ in the diagnostic criteria they use. This could therefore, result in the population studied being a more heterogeneous group than anticipated. The fact that this study did not verify the criteria used to diagnose the participants could also be considered a major limitation.

It is interesting to note that of the 389 individuals contacted for this study only 56 responded despite the fact that there was incentive provided for participation. Furthermore, of the 56 participants, 13 did not meet criteria for the study because they had indicated they did not have a diagnosis of AS but rather were family members of an individual with AS. A further five individuals did not meet criteria for the study because they reported that they were friends of an individual with AS as opposed to being diagnosed with AS themselves. If individuals who

responded to the recruitment material can be taken as a representative sample of the entire list of members that were contacted for this study, and only 59% of the respondents were actually individuals with an AS diagnosis, it then stands to reason that of the 389 individuals contacted for this study approximately 230 of them should be individuals with diagnoses of AS. This would, therefore, make the response rate for the targeted population in this study to be somewhere around 14%. However, considering AMI does not have demographic information on their member population, it may also be possible that the vast majority of its members are not actually individuals with diagnoses of AS. This could explain why the response rate was seemingly low. In fact, it is possible that the response rate appeared to be low because the recruitment email clearly indicated that this study was for individuals over the age of 18 who had a diagnosis of AS. Thus, friends and family members who would have seen that information likely would not have attempted to access the questionnaire and survey. However, at this point it is difficult to determine what exactly the response rate was. For this to be done, AMI would need more specific information on their member population. An email asking for this information, specifically, may help AMI obtain a clearer picture of their member population.

Whether the sample used in this study is representative of the population of AMI members who have a diagnosis of AS is difficult to determine but it is clear that this is a population that may be difficult to access, as has been observed in prior research endeavors. Although many efforts were taken to increase the sample size in this study, it must still be acknowledged that for all intents and purposes, the sample size used for this study was small, calling into question the overall generalizability of the results. In order to address the issues of generalizability, it is imperative that future research use larger samples. It is also extremely important, when evaluating the results of this study, to acknowledge the possibility that there

may be some fundamental difference between the individuals who participated in this study and those who chose not to. Furthermore, it is also important to recognize that of the 37 individuals with a diagnosis of AS who started the study, 5 dropped out prior to completion. Thus, it should be acknowledged that there could possibly be some fundamental difference between those individuals with a diagnosis who completed the survey and those who did not.

Considering the questionnaire and survey were sent to the potential participants via email, it is also possible that those with less access to computers would be less likely to respond, a factor that would further influence the generalizability of the results. Furthermore, it should also be acknowledged that individuals who were not employed or in school could be more likely to respond to the recruitment email due to the fact that they simply may have more time to do so than those whose days were filled with work or school. However, it is difficult address these issues without having more information about the targeted population as a whole. What can be said about the sample used in this study is that it does not appear to be representative of the overall population of Manitoba due to the fact that too large a proportion of respondents reported residing in Winnipeg. Why exactly it does not represent the geographic population of Manitoba is difficult to tell at this point but it could be speculated that individuals in Winnipeg who have a diagnosis of AS are more likely to access AMI's services because AMI is located in Winnipeg. While this may at first glance appear to be an issue of interest only to AMI, it is important to consider that this may be a fundamental problem with centralized agencies who are attempting to serve too large of a geographic area. However, in order to understand this better this issue needs to be addressed by future research.

### *Future Research*

The current study was exploratory in nature and thus, was solely aimed at uncovering some of the formal support factors that are related to QOL scores. This study found relationships between four formal support factors and QOL scores. However, the findings of this study only indicated a relationship between variables. It did not provide any evidence that formal supports have positive effects on QOL for the population in question. Therefore, future research in this area should be dedicated toward further understanding how these formal supports influence QOL and why individuals with lower QOL scores in specific domain tend to be accessing these supports more often. From the results of this study it is very difficult to determine whether the supports that were found to be correlated with QOL are having any affect on the QOL of adults with AS. Therefore, the primary recommendation is that future research on formal supports focus on experimental studies in which within-subjects measures are employed.

Although future research should continue to employ quantitative data analysis to investigate the influence of formal supports on QOL for individuals with AS, it is likely that a more thorough understanding of the motivations for accessing formal supports and the areas in which more support is needed can be determined through qualitative research methods. From the data collected for this study it is difficult to understand exactly why some people accessed some formal supports while others did not and it is difficult to understand exactly why individuals rated their QOL the way they did. Thus, the second area of focus for future research should be on qualitative methods. Qualitative research may provide further insight into some of the issues that are more difficult to uncover using quantitative studies.

Considering it has been suggested that there may be differences in the amount of support received by individuals with AS and other autism spectrum disorders, it could also be interesting

to compare the different disorders along the autism spectrum to see if it can be determined whether there are any noticeable differences in QOL scores. If differences are found between groups when factors, such as cognitive abilities, are controlled for, it could be evidence to suggest that the amount of support provided does make a difference in QOL for individuals with AS. With the results of this study not much can be said regarding how much formal supports can change QOL. Therefore, it is imperative that future research in this area employ more appropriate methods to obtain this information. A comparative analysis of differences in QOL between individuals with AS and individuals with HFA may be an appropriate third step in unraveling the effects that support can have on these populations.

As mentioned earlier, the sample size used in this study also clearly posed a problem in regards to the generalizability of the results. Furthermore, the sample obtained failed to adequately represent the population distribution of Manitoba, with too large of a proportion of participants indicating that they were currently living in Winnipeg as opposed to areas in Manitoba outside of Winnipeg. Thus, the sample obtained cannot be generalized to the overall population of adults in Manitoba with AS. Therefore, it is imperative that larger sample sizes be employed in future studies and that methods be undertaken to ensure that samples are representative of the geographical area intended. If AMI intends to conduct more research, the first step that needs to be taken is for them to determine what the demographics of their member population are, and then possibly to determine means of increasing the sample sizes in their research,

Considering that this study also found differences in Social QOL between individuals living in Winnipeg and those living outside of Winnipeg, it is recommended that AMI conduct further research to determine if these results can be replicated. If these results are easily



reproduced it would also be in their best interests to attempt to uncover what the possible causes for this may be. Research in this area may be of particular interest to other organizations that provide services to individuals with disabilities to determine whether they are adequately reaching the entire population they intend to serve.

The disproportionate responses between individuals living inside and outside of Winnipeg may also be a cause for concern for AMI, considering their mandate is to serve all individuals in Manitoba with AS. Exactly why they appear to have a disproportionate amount of respondents coming from Winnipeg is unknown at this time but it is likely that they are more easily accessed by those individuals who live in Winnipeg, considering that is where AMI is currently located. Determining whether this result is also linked to the differences in Social QOL between individuals inside and outside of Winnipeg may be extremely important for AMI. If there is a link between these findings, what it may imply is that AMI's services are indeed having positive effects on their members. However, it may also indicate that their services are disproportionately affecting their members. Future research regarding these issues may be of interest, not only to AMI, but to any organizations attempting to serve large geographical areas.

### *Conclusion*

The hypothesis at the outset of this study was that at least some of the measured formal supports would correlate positively with QOL scores. This hypothesis was based on the assumption that the presence of formal supports would improve QOL for adults with AS. However, the results of this study provided no evidence to support this assumption. What this study did find is that four of the fifteen supports studied negatively correlated with QOL scores. That is, individuals who accessed these supports reported lower QOL scores. The reasons for this are not known. However, it may be hypothesized that this is simply a result of the fact that

individuals who are in need of support, and in turn have poorer QOL, are accessing more supports. This hypothesis is partially supported by the finding in the present study that individuals who reported needing more help with their daily activities also reported accessing more total supports. This result could indicate that it is actually practical life skills that are most indicative of QOL.

Future research should be aimed at determining whether formal supports can in fact improve the lives of individuals with AS. However, in order to do this, it will be necessary to employ experimental within-subjects measures to determine whether causal relationships can be established. Qualitative measures may also be of value in determining factors that are stopping some individuals from accessing specific types of supports as well as factors that are allowing others to gain access. Qualitative measures may also be useful in gaining more insight into why individuals are reporting QOL scores the way they are.

The findings of this study indicated that the member population of AMI may be disproportionately represented by individuals living in Winnipeg. Considering AMI's office is currently located in Winnipeg, this finding may simply be due to the fact that their services are more easily accessed by individuals who are located close to them. This finding is of particular interest considering individuals who reported living outside of Winnipeg also reported having lower Social QOL scores. The possibility that these findings may be linked should be of interest to AMI as well as any other organization attempting to serve large geographical areas.

## References

- American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders* (4<sup>th</sup> ed. text revision). Washington, DC: Author.
- Angermeyer, M.C., Kilian, R., & Matschinger, H. (2001). The impact of chronic illness on subjective quality of life: A comparison between general population and hospital inpatients with somatic and psychiatric diseases. *Clinical Psychology and Psychotherapy*, 8, 206-213.
- Attwood, T. (2004). *Asperger's syndrome: a guide for parents and professionals*. New York: Jessica Kingsley Publishers.
- Autism Ontario (2008). FORGOTTEN: Ontario Adults with Autism and Adults with Aspergers.
- Barnard, J., Harvey, V., Potter, D., & Prior, A. (2001). *Ignored or ineligible? The reality for adults with autism spectrum disorders: The National Autistic Society report for autism awareness week 2001*. The National Autistic Society.
- Barnhill, G.P. (2007). Outcomes in adults with Asperger syndrome. *Focus on Autism and Other Developmental Disabilities*, 22(2), 116-126.
- Baron-Cohen, S., Leslie, A.M., & Frith, U. (1985). Does the autistic child have a "theory of mind"? *Cognition*, (1), 37-46.
- Baron-Cohen, S. (1995). *Mindblindness: An essay on autism and theory of mind*. Boston: MIT Press/Bradford Books.

- Baron-Cohen, S., Jolliffe, T., Mortimore, C., & Robertson, M. (1997). Another advanced test of theory of mind: Evidence from very high functioning adults with autism or Asperger syndrome. *Journal of Child Psychology and Psychiatry*, 38(7), 813-822.
- Cohen J. (1988). *Statistical power analysis for the behavioral sciences*. Hillsdale, NJ: Erlbaum.
- Cummins, R.A. (1996). The domains of life satisfaction: An attempt to order chaos. *Social Indicators Research*, 38, 303-328.
- Cummins, R.A. (2000). Objective and subjective quality of life: An interactive model. *Social Indicators Research*, 52, 55-72.
- Dahlgren, S.O., Sandberg, A.D., & Hjelmquist, E. (2003). The non-specificity of theory of mind deficits: Evidence from children with communicative disabilities. *European Journal of Cognitive Psychology*, 15(1), 129-155.
- Dahlgren, S.O., & Trillingsgaard, A. (1996). Theory of mind in non-retarded children with autism and Asperger's syndrome. *Journal of Child Psychology and Psychiatry*, 37(6), 759-763.
- Diener, E., Sandvik, E., Seidlitz, L., & Diener, M. (1993). The relationship between income and subjective well-being: Relative or absolute. *Social Indicators Research*, 28, 195-223.
- Ehlers, S., Nyden, A., Gillberg, C., Sandberg, A.D., Dahlgren, S., Hjelmquist, E. et al. (1997). Asperger syndrome, autism and attention disorders: A comparative study of the cognitive profiles of 120 children. *Journal of Child Psychology and Psychiatry*, 38(2), 207-217.
- Eisenmajer, R., & Prior, M. (1991). Cognitive linguistic correlates of "theory of mind" ability in autistic children. *British Journal of Developmental Psychology*, 9(2), 351-364.

- Eisenmajer, R., Prior, M., Leekam, S., Wing, L., Gould, J., Welham, M., et al. (1996). Comparison of clinical symptoms in autism and Asperger's disorder. *American Academy of Child and Adolescent Psychiatry*, 35(11), 1523-1531.
- Eisenmajer, R., Prior, M., Leekam, S., Wing, L., Ong, B., Gould, J., et al. (1998). Delayed language onset as a predictor of clinical symptoms in pervasive developmental disorders. *Journal of Autism and Developmental Disorders*, 28(6), 527-533.
- Engstrom, I., Ekstrom, L., & Emilsson, B. (2003). Psychosocial functioning in a group of Swedish adults with Asperger syndrome or high-functioning autism. *Autism*, 7(1), 99-110.
- Field, A. (2005). *Discovering Statistics Using SPSS* (2nd Edition). London: Sage Publications.
- Fombonne, E. (2001). What is the prevalence of Asperger disorder? *Journal of Autism and Developmental Disorders*, 31, 363-364.
- Frith, U. (ed.). (1991). *Autism and Asperger syndrome*. Cambridge: Cambridge University Press.
- (1998). Comorbidity of Asperger syndrome: A preliminary report. *Journal of Intellectual Disability Research*, 42(4), 279-283.
- Gilchrist, A., Green, J., Cox, A., Burton, D., Rutter, M., & Le Couteur, A. (2001). Development and current functioning in adolescents with Asperger syndrome: a comparative study. *Journal of Child Psychology and Psychiatry*, 42(2), 227-240.
- Gillberg C. (1989). Asperger's syndrome in 23 Swedish children. *Developmental Medicine & Child Neurology*, 31, 529-531.

- Gillberg, C., & Ehlers, S. (1998). High-functioning people with autism and Asperger syndrome. In E. Schopler, G.B. Mesibov, & L.J. Kuncie (Eds.), *Asperger syndrome or high-functioning autism?* (pp. 79-106). New York: Plenum Press.
- Gillberg, C. (1985). Asperger's syndrome and recurrent psychosis: A case study. *Journal of Autism and Developmental Disorders*, 15(4), 389-397.
- Gladis, M.M., Gosch, E.A., Dishuk, N.M., & Crits-Cristoph, P. (1999). Quality of life: expanding the scope of clinical significance. *Journal of Consulting and Clinical Psychology*, 67(3), 320-331.
- Glatzer, W. (1991). Quality of life in advanced industrialized countries: The case of West Germany. In F. Strack, M. Argyle, and N. Schwartz (eds.), *Subjective well-being: An interdisciplinary perspective* (pp. 261-279). New York: Plenum Press.
- Happe, F.G.E. (1995). The role of age and verbal ability in the theory of mind task performance of subjects with autism. *Child Development*, 66(3), 843-855.
- Headey, B., & Wearing, A. (1989). Personality, life events, and subjective well-being: Toward a dynamic equilibrium model. *Journal of Personality and Social Psychology*, 57(4), 731-739.
- Henrich, G., & Herschbach, P. (2000). Questions on life satisfaction (FLZ<sup>M</sup>) - A short questionnaire for assessing subjective quality of life. *European Journal of Psychological Assessment*, 16(3), 150-159.
- Hepworth, S.J. (1980). Moderating factors of the psychological impact of unemployment. *Journal of Occupational Psychology*, 53, 139-145.

- Howlin, P. (2000). Outcome in adult life for more able individuals with autism or Asperger syndrome. *Autism*, 4(1), 63-83.
- Howlin, P. (2003). Outcome in high-functioning adults with autism with and without early language delays: Implications for the differentiation between autism and Asperger syndrome. *Journal of Autism and Developmental Disorders*, 33(1), 3-13.
- Howlin, P., Good, S., Hutton, J., & Rutter, M. (2004). Adult outcome in children with autism. *Journal of Child Psychology and Psychiatry*, 45, 212-229.
- Howlin, P., & Asgharian, A. (1999). The diagnosis of autism and Asperger syndrome: Findings from a survey of 770 families. *Developmental Medicine & Child Neurology*, 41, 834-839.
- Howlin, P., & Yates, P. (1999). The potential effectiveness of social skills groups for adults with autism: Information update. *Autism*, 3(3), 299-307.
- Hurlburt, K., & Chalmers, L. (2004). Employment and adults with Asperger syndrome. *Focus on Autism and Other Developmental Disabilities*, 19(4), 215-222.
- Jennes-Coussens, M., Magill-Evans, J., & Koning, C. (2006). The quality of life of young men with Asperger syndrome. *Autism*, 10(4), 403-414.
- Kawaga-Singer, M. (1993). Redefining health: Living with cancer. *Social Science and Medicine*, 37, 295-304.
- Kjelgaard, J., & Tager-Flusberg, H. (2001). An investigation of language impairment in autism: Implications for genetic subgroups. *Language and Cognitive Processes*, 16, 287-308.

- Klin, A., Volkmar, F.R., Sparrow, S.S., Cicchetti, D.V., & Rourke, B.P. (1995). Validity and neuropsychological characterization of Asperger syndrome: Convergence with nonviable learning disabilities syndrome. *Journal of Child Psychology and Psychiatry*, 36, 1127-1140.
- Klin, A., & Volkmar, F.R. (2000). Treatment and intervention guidelines for individuals with Asperger syndrome. In A. Klin, F.K. Volkmar, & S.S. Sparrow (Eds.), *Asperger syndrome* (pp. 340-366). New York: The Guilford Press.
- Lotspeich, L.J., Kwon, H., Schumann, C.M., Fryer, S.L., Goodlin-Jones, B.L., Buonocore, M.H., et al. (2004). Investigation of neuroanatomical differences between autism and Asperger syndrome. *Archives of General Psychiatry*, 61(3), 291-298.
- MacFabe, D., Cain, D.P., Rodriguez-Capote, K., Franklin, A.E., Hoffman, J.E., Boon, F., et al. (2007). Neurobiological effects of intraventricular propionic acid in rats: Possible role of short chain fatty acids on the pathogenesis and characteristics of autism spectrum disorders. *Behavioural Brain Research*, 176, 149-169.
- Manjiviona, J., & Prior, M. (1995). Comparison of Asperger syndrome and high-functioning autistic children on a test of motor impairment. *Journal of Autism and Developmental Disorders*, 25(1), 23-39.
- Mattila, M., Kielinen, M., Jussila, K., Linna, S., Bloigu, R., Ebeling, H., et al. (2007). An epidemiological and diagnostic study of Asperger syndrome according to four sets of diagnostic criteria. *Journal of the American Academy of Child and Adolescent Psychiatry*, 46(5), 636-646.



- Mawhood, L., & Howlin, P. (1999). The outcome of a supported employment scheme for high-functioning adults with autism or Asperger syndrome. *Autism*, 3(3), 229-254.
- Mayes, S.D., Calhoun, S.L., & Crites, D.L. (2001). Does DSM-IV Asperger's disorder exist? *Journal of Abnormal Child Psychology*, 29(3), 263-271.
- Melbourne WHOQOL Field Study Centre (2000). *The World Health Organization quality of life (WHOQOL) study: Australian WHOQOL-100, WHOQOL-BREF, & CA-WHOQOL instruments: User's manual and interpretation guide*. University of Melbourne Department of Psychiatry and St. Vincent's Mental Health Service.
- Miller, J.N., & Ozonoff, S. (1997). Did Asperger's cases have Asperger disorder? A research note. *Journal of Child Psychology and Psychiatry*, 38, 247-251.
- Miller, J.N., & Ozonoff, S. (2000). The external validity of Asperger disorder: Lack of evidence from the domain of neuropsychology. *Journal of Abnormal Psychology*, 109(2), 227-238.
- Missiuna, C., Pollock, N., Caltagirone, L., Maggioira, K., & Zwaigenbaum, L. (2003). McMaster University, Institute for Applied Health Sciences. *Services for children with Asperger's syndrome in Canada: An environmental scan*. Retrieved April 10, 2008, from the CanChild web site: [http://www.canchild.ca/Portals/0/in\\_brief/pdf/IB022003Asperger.pdf](http://www.canchild.ca/Portals/0/in_brief/pdf/IB022003Asperger.pdf)
- Oyane, N.M.F., & Bjorvatn, B. (2005). Sleep disturbances in adolescents and young adults with autism and Asperger syndrome. *Autism*, 9(1), 83-94.
- Ozonoff, S., Pennington, B.F., & Rogers, S.J. (1991). Executive function deficits in high-functioning autistic individuals: Relationships to theory of mind. *Journal of Child Psychology and Psychiatry*, 32(7), 1081-1105.

- Ozonoff, S., Rogers, S.J., & Pennington, B.F. (1991). Asperger's syndrome: Evidence of an empirical distinction from high-functioning autism. *Journal of Child Psychology and Psychiatry*, 32(7), 1107-1122.
- Ozonoff, S., Garcia, N., Clark E., & Lainhart, J.E. (2005). MMPI-2 personality profiles of high functioning adults with autism spectrum disorders. *Assessment*, 12(1), 85-96.
- Padilla, G.V., Mishel, M.H., & Grant, M.M. (1992). Uncertainty, appraisal and quality of life. *Quality of Life Research*, 1, 155-165.
- Pomeroy, J.C. (1998). Subtyping pervasive developmental disorder. In E. Schopler, G.B. Mesibov, & L.J. Kuncie (Eds.), *Asperger syndrome or high-functioning autism?* (pp. 29-60). New York: Plenum Press.
- Prior, M., Eisenmajer, R., Leekam, S., Wing, L., Gould, J., Ong, B., et al. (1998). Are there subgroups within the autistic spectrum? A cluster analysis of a group of children with autistic spectrum disorders. *Journal of Child Psychology and Psychiatry*, 39(6), 893-902.
- Renty, J., & Roeyers, H. (2006). Quality of life in high-functioning adults with autism spectrum disorder: The predictive value of disability and support characteristics. *Autism*, 10(5), 511-524.
- Rogers, S.J. (1996). Brief Report: Early intervention in autism. *Journal of Autism and Developmental Disorders*, 26(2), 243-246.
- Ruble, L., & Dalrymple, N. (1996). An alternative view of outcome in autism. *Focus on Autism and Other Developmental Disabilities*, 11(1), 3-14.

Rutherford, M. D., Baron-Cohen, S., & Wheelwright, S. (2002). Reading the mind in the voice:

A study with normal adults and adults with Asperger syndrome and high functioning autism. *Journal of Autism and Developmental Disorders*, 32(3), 189-194.

Schalock, R.L. (2000). Three decades of quality of life. *Focus on Autism and Other*

*Developmental Disabilities*, 15, 116-127.

Schalock, R.L. (2004). The concept of quality of life: what we know and do not know. *Journal of*

*Intellectual Disability Research*, 48(3), 203-216.

Schopler, E., & Mesibov, G.B. (1998). Introduction. In E. Schopler, G.B. Mesibov, & L.J. Kuncie

(Eds.), *Asperger syndrome or high-functioning autism?* (pp. 3-9). New York: Plenum Press.

Schopler, E., Mesibov, G.B., & Kuncie, L.J. (Eds.) (1998). *Asperger syndrome or high-*

*functioning autism?* New York: Plenum Press.

Statistics Canada (2006). *2006 Census*. Retrieved July 30, 2009, from the Statistics Canada

website: [www.statcan.gc.ca](http://www.statcan.gc.ca).

Stedman, T. (1996). Approaches to measuring quality of life and their relevance to mental health.

*Australian and New Zealand Journal of Psychiatry*, 30, 731-740.

Szatmari, P. (1998). Differential diagnosis of Asperger disorder. In E. Schopler, G.B. Mesibov,

& L.J. Kuncie (Eds.), *Asperger syndrome or high-functioning autism?* (pp. 61-76). New York: Plenum Press.

- Szatmari, P., Bryson, S.E., Streiner, D.L., Wilson, F., Archer, L., & Ryerse, C. (2000). Two-year outcome of preschool children with autism or Asperger's syndrome. *American Journal of Psychiatry*, 157(12), 1980-1987.
- Szatmari, P., Bryson, S.E., Boyle, M.H., Streiner, D.L., & Duku, E. (2003). Predictors of outcome among high functioning children with autism and Asperger syndrome. *Journal of Child Psychology and Psychiatry*, 44(4), 520-528.
- Szatmari, P. (2005). Developing a research agenda in Asperger syndrome. In K. Stoddart (Ed.), *Children, youth and adults with Asperger syndrome: Integrating multiple perspectives*. (pp. 229-241). London: Jessica Kingsley Publishers.
- Skevington, S.M., Lofty, M., & O'Connell, K.A. (2004). The World Health Organization's WHOQOL-BREF quality of life assessment: Psychometric properties and results of the international field trial: A report from the WHOQOL group. *Quality of Life Research*, 13, 299-310.
- Suurmeijer, T.P.B.M., Reuvekamp, M.F., & Aldenkamp, B.P. (2001). Social functioning, psychological functioning, and quality of life in epilepsy. *Epilepsia*, 42(9), 1160-1168.
- Tabachnik, B.G., & Fidell, L.S. (2007). *Using Multivariate Statistics* (5<sup>th</sup> edition). Toronto: Pearson Education.
- Tantum, D. (1988). Annotation: Asperger's syndrome. *Journal of Child Psychology and Psychiatry*, 29(3), 245-255.
- Tantum, D. (2003). The challenge of adolescents and adults with Asperger syndrome. *Child and Adolescent Psychiatric Clinics of North America*, 12, 143-163.

- Tantum, D. (2000). Psychological disorder in adolescents and adults with Asperger syndrome. *Autism*, 4(1), 47-62.
- Trompenaars, F.J., Masthoff, E.D., Van Heck, G.L., Hodiament, P.P., & De Vries, J. (2006). The WHO quality of life assessment instrument (WHOQOL-100): Investigating its discriminant ability for psychiatric outpatients. *European Journal of Psychological Assessment*, 22(3), 207-215.
- Tsai, L.Y. (1992). Diagnostic issues in high-functioning autism. In E. Schopler & G.B. Mesibov (Eds.), *High-functioning individuals with autism* (pp. 11-40). New York: Plenum Press.
- Wing, L. (1981). Asperger syndrome: A clinical account. *Psychological Medicine*, 11, 115-129.
- Wing, L. (1997). The history of ideas on autism. *Autism*, 1(1), 13-23.
- Wing, L. (1998). The history of Asperger syndrome. In E. Schopler, G.B. Mesibov, & L.J. Kunc (Eds.), *Asperger syndrome or high-functioning autism?* (pp. 11-28). New York: Plenum Press.
- Wing, L. (2000). Past and future research on Asperger syndrome. In A. Klin, F.R. Volkmar, & S. Sparrow (Eds.), *Asperger syndrome* (pp. 418-432). New York: Guilford Press.
- WHOQOL Group (1998). Development of the World Health Organization WHOQOL-BREF Quality of Life Assessment. *Psychological Medicine*, 28, 551-558.
- WHOQOL Group (1999). The World Health Organization WHOQOL-100: Tests of the universality of quality of life in 15 different cultural groups worldwide. *Health Psychology*, 18(5), 495-505.

World Health Organization. (1992). *ICD-10: International statistical classification of diseases and related health problems, tenth revision*. Geneva: World Health Organization.

## **Appendix A: Questionnaire**

1. Are you:

- An individual with Asperger's syndrome
- An individual that doesn't have Asperger's syndrome but is a family member of an individual with Asperger's syndrome
- An individual that doesn't have Asperger's syndrome but is a friend of an individual with Asperger's syndrome

2. Which age category describes you best?

- Under 18
- 18-24
- 25-29
- 30-34
- 35-39
- 40+

3. Where do you live?

- In Winnipeg
- In Manitoba but outside of Winnipeg
- Outside of Manitoba

4. Who provided you with your diagnosis of Asperger syndrome?

- A psychiatrist
- A psychologist
- A medical doctor
- A team that included either a psychiatrist, a psychologist, or a medical doctor
- I am self-diagnosed
- Other (please specify) \_\_\_\_\_
- I don't know

5. Are you:

- Male
- Female

6. How old were you when you were diagnosed with Asperger syndrome?

- 0-11
- 12-18
- 19-24
- Older than 24
- Never diagnosed
- I don't know



7. Did you have a diagnosis of something else before you were diagnosed with Asperger syndrome?

- Yes (If yes, please state your previous diagnosis?) \_\_\_\_\_
- No
- I don't know

8. Have you been diagnosed with any of the following? (check all that apply)

- Depression
- Anxiety
- Obsessive Compulsive Disorder
- Tourette's Syndrome
- Attention Deficit Hyperactivity Disorder
- Oppositional Defiance Disorder
- Personality Disorder (please specify) \_\_\_\_\_
- Other (please specify) \_\_\_\_\_

9. Do you live alone?

- Yes
- No

10. Where do you live?

- With my parents
  - In a group home
  - In my own apartment or house with drop in support
  - In my own apartment or house with live in support
  - In my own apartment or house without support
  - Other (please describe)
- 
- 

11. If you live in your own apartment or house who provides you with the most support?

- Family
- Friends
- Professional / Support Worker
- I don't have any support
- I don't live in my own apartment or house

12. Did you graduate from high school?

- Yes
- No
- If no, what grade did you complete? \_\_\_\_\_

13. When you were in high school did you have a transition plan created, where you talked with others (family, teachers, social worker or anyone else) about your plans after graduation?

- Yes
- No
- I don't know

14. How did you feel about leaving high school?

- Anxious all the time
- Anxious some of the time
- Excited / happy
- Unsure
- Other (please describe) \_\_\_\_\_

15. Since you left school, have you taken any other courses?

- Yes
- No
- I am still taking courses

16. If you have taken other courses have you completed a certificate or obtained a degree?

- Yes (please specify) \_\_\_\_\_
- No
- I have not taken other courses

17. Do you have a job right now?

- Yes: Full-time paid
- Yes: Part-time paid
- Yes: Voluntary work unpaid
- Other (please specify) \_\_\_\_\_
- No

18. If you are currently employed, does the job you have now relate to what you learned in university, college, or a training program?

- Yes
- No
- I am not currently employed
- Somewhat (please explain)

---

---

---

19. From the age of 18 how long have you been in some form of employment?

- I have not worked at all
- Less than 12 months
- Between 1 and 4 years
- 5 years or more

20. If you are employed, how satisfied are you with your job?

- Not at all
- Somewhat
- Very
- Completely
- I am not employed

21. Does your family give you financial support (money)?

- Yes, on a regular basis
- Yes, but only on rare occasions
- No

22. Do you need help to:

	Yes	No
Prepare a meal	<input type="checkbox"/>	<input type="checkbox"/>
Do housework	<input type="checkbox"/>	<input type="checkbox"/>
Pay Bills	<input type="checkbox"/>	<input type="checkbox"/>
Manage Money	<input type="checkbox"/>	<input type="checkbox"/>
Shop for clothes, groceries, and other items	<input type="checkbox"/>	<input type="checkbox"/>
Do laundry	<input type="checkbox"/>	<input type="checkbox"/>
Deal with letters / correspondence (such as from the government, income tax)	<input type="checkbox"/>	<input type="checkbox"/>
Assist with personal care / hygiene	<input type="checkbox"/>	<input type="checkbox"/>
Make medical appointments	<input type="checkbox"/>	<input type="checkbox"/>
Attend medical appointments	<input type="checkbox"/>	<input type="checkbox"/>

23. If you were diagnosed with Asperger syndrome before you turned 18, have you had assistance from the government since you have turned 18?

- Yes
- No
- I don't know
- I wasn't diagnosed with Asperger syndrome until after I turned 18

24. If you were diagnosed with Asperger syndrome after you turned 18 did you have problems getting assistance from the government prior to you turning 18?

- Yes
- No
- I don't know
- I was diagnosed prior to turning 18

25. Are you receiving any support and/or services from an agency at this time?

- Yes, from a government agency
- Yes, from a non-governmental agency
- No
- I don't know

26. Do you have a social worker, community health worker, or case manager at this time? If so have they assisted you in creating a person-centred plan that is regularly reviewed?

- Yes, I have someone working with me at this time and we have created a regularly reviewed personal plan
- Yes, I have someone working with me at this time but we have not created a regularly reviewed personal plan
- Yes, I have someone working with me at this time and we have created a plan but it is not reviewed regularly
- No I do not have someone working with me at this time
- I don't know

27. Which of the following types of support do you receive? (Check all that apply.)

- Social groups
- Employment support
- Counselling
- Education
- Psychology
- Psychiatry
- Physiotherapy
- Advocacy (someone to assist you to voice your rights)
- Social skills training
- Daily living support
- Occupational therapy
- Peer support
- None
- Other (please describe)

---

---



28. Which of the following types of support that you are currently not receiving do you think would be most beneficial for you? (Check all that apply.)

- Social groups
- Advocacy (someone to assist you to voice your rights)
- Employment support
- Counselling
- Education
- Psychology
- Psychiatry
- Social skills training
- Daily living support (see question 21)
- Occupational therapy
- Physiotherapy
- Peer support
- None
- Other (please describe)

---

---

---

29. Do you have enough assistance or services to meet your needs?

- Yes
- No
- I don't know

30. Do you agree or disagree with the following statements?

	I agree	I neither agree nor disagree	I disagree
With more support I would be able to live more independently.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
With more assistance I think I would be able to work more.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
With more assistance I think I would feel less isolated.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
With more assistance I would be more able to do the things I want to do.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
With more assistance I think my general health would improve.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have experienced anxiety because of a lack of assistance.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have experienced depression because of a lack of assistance.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
I have experienced severe mental health difficulties because of a lack of assistance.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

31. Since the age of 18 have you been a victim of a crime?

- Yes
- No

32. Since the age of 18 have you been charged with a crime?

- Yes
- No

33. Since the age of 18 have you been accused of a crime you did not commit?

- Yes
- No

34. Since the age of 18 have you regularly used drugs not prescribed to you by your doctor (such as marijuana, cocaine, ecstasy, etc.)?

- Yes (please specify how often you use them) \_\_\_\_\_
- No
- I have tried drugs but I do not use them regularly

35. Do you drink alcohol at least once a week?

- Yes (please specify approximately how many drinks you have per week) \_\_\_\_\_
- No

36. How easy do you find it to make friends?

- Very easy
- Easy
- Neither easy nor hard
- Hard
- Very hard
- I don't have any friends

37. How satisfied are you with your current friendships?

- Very satisfied
- Somewhat satisfied
- Not satisfied nor dissatisfied
- Dissatisfied
- Very dissatisfied

38. Do you have a best friend?

- Yes, I have one best friend
- Yes, I have more than one best friend
- No

39. Have you had any romantic relationships?

- Yes
- No

40. Are you:

- Single
- Married
- Living with a partner
- Dating

41. Where do you get most of your money?

- Pay from work
- From the government (Employment and Income Assistance or Canada Pension Plan)
- Parents
- Other (please specify) \_\_\_\_\_

42. Have you been diagnosed with any serious illness related to your physical health (such as diabetes, epilepsy, migraines, etc.)?

No

Yes (please specify) \_\_\_\_\_

43. Do you have any physical health problems that are making it difficult to carry out your daily activities?

- No
- Yes (please explain)

---

---

---

44. Do you have any physical health problems that you feel have not been adequately treated?

- No
- Yes (please explain)

---

---

---

45. Do you have any chronic (long lasting, continuing) pain

- No
- Yes (please explain)

---

---

---

For the following questions please check the box beside the number that best describes how you feel for each question:

1 = Never

2 = Rarely (less than once a month)

3 = Sometimes (At least once a month)

4 = Often (At least once a week)

5 = Always (Several times a day)

46. How often do you feel depressed?

☐ 1☐ 2☐ 3☐ 4☐ 5

47. How often do you feel anxious?

☐ 1☐ 2☐ 3☐ 4☐ 5

For the following question please check the box beside the number that best describes how you feel for each question:

1 = Extremely poor (or far worse than the average person)

2 = In between extremely poor and average

3 = Average (the same as most people)

4 = In between average and excellent

5 = Excellent (or very satisfied)

48. How would you rate your social life?

☐ 1☐ 2☐ 3☐ 4☐ 5

## Appendix B: WHOQOL-BREF Survey

WHA/MNH/PSF/97.6  
Page 16

I.D. number

--	--	--	--

### ABOUT YOU

Before you begin we would like to ask you to answer a few general questions about yourself: by circling the correct answer or by filling in the space provided.

What is your **gender**?

Male

Female

What is your **date of birth**?

/ /

Day / Month / Year

What is the highest **education** you received?

None at all

Primary school

Secondary school

Tertiary

What is your **marital status**?

Single

Separated

Married

Divorced

Living as married

Widowed

Are you currently **ill**?

Yes

No

If something is wrong with your health what do you think it is? \_\_\_\_\_ illness/ problem

### Instructions

This assessment asks how you feel about your quality of life, health, or other areas of your life. **Please answer all the questions.** If you are unsure about which response to give to a question, **please choose the one** that appears most appropriate. This can often be your first response.

Please keep in mind your standards, hopes, pleasures and concerns. We ask that you think about your life **in the last two weeks**. For example, thinking about the last two weeks, a question might ask:

	Not at all	Not much	Moderately	A great deal	Completely
	1	2	3	4	5
Do you get the kind of support from others that you need?					

You should circle the number that best fits how much support you got from others over the last two weeks. So you would circle the number 4 if you got a great deal of support from others as follows.

	Not at all	Not much	Moderately	A great deal	Completely
	1	2	3	4	5
Do you get the kind of support from others that you need?					

You would circle number 1 if you did not get any of the support that you needed from others in the last two weeks.

Please read each question, assess your feelings, and circle the number on the scale for each question that gives the best answer for you.

		Very poor	Poor	Neither poor nor good	Good	Very good
1(G1)	How would you rate your quality of life?	1	2	3	4	5

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
2 (G4)	How satisfied are you with your health?	1	2	3	4	5

The following questions ask about **how much** you have experienced certain things in the last two weeks.

		Not at all	A little	A moderate amount	Very much	An extreme amount
3 (F1.4)	To what extent do you feel that physical pain prevents you from doing what you need to do?	1	2	3	4	5
4(F11.3)	How much do you need any medical treatment to function in your daily life?	1	2	3	4	5
5(F4.1)	How much do you enjoy life?	1	2	3	4	5
6(F24.2)	To what extent do you feel your life to be meaningful?	1	2	3	4	5

		Not at all	A little	A moderate amount	Very much	Extremely
7(F5.3)	How well are you able to concentrate?	1	2	3	4	5
8 (F16.1)	How safe do you feel in your daily life?	1	2	3	4	5
9 (F22.1)	How healthy is your physical environment?	1	2	3	4	5

The following questions ask about **how completely** you experience or were able to do certain things in the last two weeks.

		Not at all	A little	Moderately	Mostly	Completely
10 (F2.1)	Do you have enough energy for everyday life?	1	2	3	4	5
11 (F7.1)	Are you able to accept your bodily appearance?	1	2	3	4	5
12 (F18.1)	Have you enough money to meet your needs?	1	2	3	4	5
13 (F20.1)	How available to you is the information that you need in your day-to-day life?	1	2	3	4	5
14 (F21.1)	To what extent do you have the opportunity for leisure activities?	1	2	3	4	5

		Very poor	Poor	Neither	Good	Very good
--	--	-----------	------	---------	------	-----------



MSA/MNH/PSF/97.6  
Page 18

				poor nor good		
15 (F9.1)	How well are you able to get around?	1	2	3	4	5

The following questions ask you to say how **good or satisfied** you have felt about various aspects of your life over the last two weeks.

		Very dissatisfied	Dissatisfied	Neither satisfied nor dissatisfied	Satisfied	Very satisfied
Phys	16 (F3.3)	1	2	3	4	5
Phys	17 (F10.3)	1	2	3	4	5
Phys	18(F12.4)	1	2	3	4	5
Psy	19 (F6.3)	1	2	3	4	5
Soc.	20(F13.3)	1	2	3	4	5
Soc.	21(F15.3)	1	2	3	4	5
Soc.	22(F14.4)	1	2	3	4	5
Env.	23(F17.3)	1	2	3	4	5
Env.	24(F19.3)	1	2	3	4	5
Env.	25(F23.3)	1	2	3	4	5

The following question refers to **how often** you have felt or experienced certain things in the last two weeks.

		Never	Seldom	Quite often	Very often	Always
Psy	26 (F8.1)	1	2	3	4	5

Did someone help you to fill out this form?.....

How long did it take to fill this form out?.....

**Do you have any comments about the assessment?**

.....  
.....

**THANK YOU FOR YOUR HELP**

If you are interested in the possibility of a future follow-up interview regarding this study,  
please contact Brendan Newton via email at [bjn429@mail.usask.ca](mailto:bjn429@mail.usask.ca)

}

## Appendix C: Application to the Behavioural Research Ethics Board



### Behavioural Research Ethics Board (Beh-REB)

#### *Information Required:*

##### **Name of researcher(s)**

Researcher: Brendan Newton

Supervisor: Tim Claypool

Department: Educational Psychology and Special Education

##### **1a. Name of student(s)**

Brendan Newton (M.Ed Candidate)

##### **1b. Anticipated start date of the research study (phase) and the expected completion date of the study (phase).**

March 1, 2009 – August 1, 2009

##### **2. Title of Study**

An Exploratory Study of Formal Support Factors and Quality of Life for Adults with Asperger's Syndrome.

##### **3. Abstract (100-250 words)**

Several studies have shown that adult outcomes for individuals with Asperger's syndrome tend to be poor. However, few studies, to date, have attempted to examine the perceived quality of life for this population. Although research has shown that discrepancies between needed formal support and received formal support are significantly related to quality of life in adults with higher-functioning autism spectrum disorders, to date, no research has been conducted to determine which formal support variables predict quality of life. The proposed study will be designed to gather information from adults with Asperger's Syndrome to determine whether specific formal support variables can significantly predict quality of life in adults with Asperger's syndrome. Participants will be sent a questionnaire that will include questions pertaining to formal support as well as a survey designed by the World Health Organization to measure quality of life in four domains.

##### **4. Funding**

This research is being conducted on behalf of Asperger's Manitoba Incorporated (AMI), a non-profit organization that operates out of Winnipeg, Manitoba. This organization has agreed to cover any costs associated with the completion of this project.

**5. Expertise**

The participants in this research project will be adults with Asperger's syndrome. Since beginning my graduate program I have gained experience working with individuals with autism spectrum disorders through employment with Autism Services in Saskatoon. From October 2007 to December 2008 I was employed as the assistant coordinator of the Guys' Club, a social group for males with higher-functioning autism spectrum disorders. Through my employment in this program I was able to gain first-hand experience of many of the strengths and weaknesses that are common to higher-functioning individuals on the autism spectrum. Furthermore, I was able to gain a more thorough understanding of some of the factors that both negatively and positively affect the quality of life for these individuals.

At present I am currently studying School and Counselling Psychology in the Department of Educational Psychology and Special Education in the College of Education. In this program I have had a number of opportunities to explore the literature in regards to autism spectrum disorders and as a result have gained a wealth of knowledge in this area. I have also co-authored a test review of a diagnostic assessment tool for autism spectrum disorders in the Journal of Psychoeducational Assessment (December 2008, Vol. 26, No. 4)

**6. Conflict of Interest**

N/A

**7. Participants**

Participants will be recruited from the pool of members of Asperger's Manitoba Incorporated (AMI). Once approval for the research is given an email will be sent out by AMI to all members indicating the purpose of the research, the name and contact information of the primary researcher and supervisor, a brief description of the procedure for participation, the time commitment necessary for participation, and a description of the targeted participants. AMI members will be contacted three times via email regarding participation in this study. The second and third time the email is sent out, participants will be informed that if they do choose to participate in the study, they will have the option of entering a draw for a \$100 gift certificate to their choice of either Futureshop, Walmart, or Superstore at the end of the survey. To ensure confidentiality, however, once the survey is completed participants will be directed to a page on the AMI website where they can enter their contact information for the purposes of the draw only. The third email sent out will again be sent out to all AMI members. However, it will state that anyone who has completed the survey already can ignore the email. The third email will also be sent out to individuals who have recently contacted AMI regarding their services but have not yet signed up for membership with the organization.

The questionnaire and survey that will be used for data collection will be sent with the initial recruitment email, as a link to a website. Potential participants will be initially directed toward a consent which they will need to acknowledge by checking a box that will be located beside the statement "I agree to consent to participate in this research

study”. A box will also appear below that, located beside the statement “I do not agree to consent to participate in this research study”. Individuals who consent will then be directed to the questionnaire and survey. Those who do not consent will be directed to a web page that will have written “Thank you for your time”.

The initial email will indicate that this research study is intended for adults currently living in Manitoba who have Asperger's syndrome. This statement is of great importance due to the fact that some members of AMI do not have a diagnosis of Asperger's syndrome but rather are family members of individuals who do. In order to decrease the chances of receiving data from individuals who are outside of the selection criteria, four questions have been included on the first page of the questionnaire in an attempt to identify those who qualify for the study and those who do not. These questions pertain to member status (individual with Asperger's syndrome or a family member) age, location of current residence, and if diagnosed, the origin of diagnosis. Any individuals who are under the age of 18, living outside of Manitoba, or have not received a diagnosis from a qualified professional will not be included in the data analysis. Data will be collected regarding the numbers of diagnosed individuals who respond in comparison to those respondents who are simply family members of a diagnosed individual. Participants indicating their status as a family member will be immediately directed away from the questionnaire to a web page thanking them for their time and once again indicating the purpose of the study.

## **8. Consent**

Participants will be recruited via email by AMI. The recruitment email will include a link to a website where the participants can take part in the study. Potential participants will be directed initially to a web page that will indicate the title of the study, the purpose of the research, the target participant pool, the procedure for participation, the name and contact information of the primary researcher and supervisor, the time commitment expected, and information regarding the participants' right to withdraw from participation. The consent page will also indicate that participation in the research project is completely voluntary.

### ***a) Alternative consent protocols***

Participants will have the option of checking a box that indicates that they are willing to participate or one that indicates that they are not willing to participate. Checking the box indicating willingness to participate will direct the potential participants to the questionnaire and survey. Completion of the entire questionnaire and survey will also double as an indication of full consent.

### ***b) Recruitment from organizations***

A verbal agreement has been made between the primary researcher and Asperger's Manitoba (AMI) Incorporated regarding the proposed research. In the fall of 2007 it was brought to the attention of the primary researcher that AMI had an interest in collaborating with a student researcher to have data collected on the current quality of life of their member population. A written statement regarding

the agreement between AMI and the primary researcher has been attached in the appendix.

*c) Children under 18 years of age*

N/A

*d) Participants are in a dependent relationship to the researcher*

N/A

*e) Participants are not able to given either consent or assent*

N/A

*f) Participant-Observation research*

N/A

*g) Research involving small groups*

N/A

**9. Methods/Procedures**

Prospective participants will be sent, via email, a 48-item questionnaire with items pertaining to demographic data, physical health, psychological health, social relationships, living conditions, substance use, and involvement with the justice system. Participants will also be sent the WHOQOL-BREF (World Health Organization Quality of Life Brief Version) survey, a condensed version of a 100-item quality of life survey that has been developed by the World Health Organization. The WHOQOL-BREF is a 26-item survey that contains one item from each of the 24 components of quality of life included in the WHOQOL-100. The 24 items form four domains (physical health, psychological health, environment, social relationships) that are each intended to measure an aspect of quality of life. An additional two items have been included to provide a measure of overall quality of life and general health. However, these final two items are not included in the overall scoring. Each item on the survey is scored on a five-point likert scale. Descriptive statistics will be used to analyse the data collected from the 48-item questionnaire. Additionally, data collected from items pertaining to formal support will be correlated with quality of life scores from the four domains on the WHOQOL-BREF to determine possible relationships. A multiple regression will be used if any formal support factors are found to contribute a significant amount of variance to the quality of life scores.

At the end of the questionnaire and survey participants will be asked if they would be willing to leave contact information for possible follow-ups in the future. However, follow-ups will only be conducted if participant numbers are low enough that they are not sufficient to conduct the statistical tests needed for the proposed analysis. If participants do indicate interest in being contacted for future contact, they will be prompted to leave their name and phone number. However, this information will only be used for follow-up contact purposes and therefore, will otherwise be kept confidential.

**10. Storage of Data**

Dr. Tim Claypool is the supervisor of the primary researcher. All data collected during the course of this study will be stored in Dr. Claypool's office at the University of Saskatchewan for at least five years after the completion of the research. All identifying information, such as consent forms and master lists will be stored separately from the data. The master list will be destroyed once data collection is completed. If I, Brendan Newton, (the primary researcher) choose to destroy the data after five years, all materials included as part of the study will be destroyed appropriately.

**11. Dissemination of Results**

The data collected in the proposed research will be use primarily for the completion of the thesis requirement in the School and Counselling Psychology Master's degree program in the Department of Educational Psychology and Special Education. The proposed research will be conducted in conjunction with Asperger's Manitoba Incorporated (AMI), a non-profit organization out of Winnipeg Manitoba, that provides services and education to individual's in Manitoba who have Asperger's syndrome. Once the data has been collected and analysed, a report summarizing the results of the research will be submitted to the board of directors at AMI. AMI intends to use the results of the research to advocate to the government of Manitoba on behalf of the members of their organization. The final report will also be posted on the AMI website. Upon completion of the thesis, the data collected may be used to submit an entry to a refereed journal.

**12. Risk, Benefits, and Deception**

The proposed research may be viewed as beneficial in that data collected in this research will be used by Asperger's Manitoba Incorporated (AMI) in an effort to advocate for more funding and support from the provincial government of Manitoba for individuals with Asperger's syndrome.

Many of the questions included in both the questionnaire and the survey that will be employed in the proposed research are of a personal and sensitive nature. As a result it is possible that some participants may feel discomfort or stress while participating in the research. However, participants will be told that they are free to discontinue at any point during the process.

**13. Confidentiality**

Participants in this study will be contacted through email only by AMI. The researchers will not be provided with any identifying information or contact information of any of the participants without the full consent of the AMI members themselves. Participants will submit their responses to the items included in the questionnaire and survey online and will not have their name attached to the data. Participants will be asked if they are willing to be contacted for a possible follow-up in the future. However, this follow-up will only be conducted if participant numbers are significantly low. If participants indicate interest in the follow-up, they will be asked to contact the research team. However, this information will only be used for the collection of follow-up data and therefore, will otherwise be kept confidential. Identifying information, such as consent

forms will be stored separate from the data. Master lists will be destroyed once the data has been collected and are no longer necessary.

Although participants will be informed that they will have the option of entering a draw for a gift certificate once they have completed the survey, their contact information will still be kept confidential from the research team. To ensure this, once the survey has been completed participants, who choose to enter their name into the draw, will be given the option of going to a page on the AMI website where they can provide AMI with their contact information for the purposes of the draw only. Information provided for this will not be available to the research team.

**14. Data/Transcript Release**

N/A

**15. Debriefing and feedback**

Upon completion of the research all members of Asperger's Manitoba Incorporated (AMI) will be sent an email briefly explaining the results of the study and what will be done with the results in terms of advocacy. A link will also be provided to the AMI website, which will contain the complete report that will be written for AMI.

**16. Required Signature**

\_\_\_\_\_  
Brendan Newton (Student Researcher)

\_\_\_\_\_  
Date

\_\_\_\_\_  
Tim Claypool (Supervisor)

\_\_\_\_\_  
Date

\_\_\_\_\_  
David Mykota (Department Head)

\_\_\_\_\_  
Date

**17. Required Contact Information**

***Student Researcher***

Brendan Newton

*Phone:* 966-7720

*Fax:* 966-7719

*Email:* bjn429@mail.usask.ca

***Mailing Address:***

Department of Educational Psychology and Special Education,



College of Education,  
University of Saskatchewan,  
28 Campus Dr., Saskatoon, SK.  
S7N 0X1

***Research Supervisor***

Tim Claypool  
*Phone:* 966-6931  
*Fax:* 966-7719  
*Email:* tim.claypool@usask.ca

***Mailing Address:***

Department of Educational Psychology and Special Education,  
College of Education,  
University of Saskatchewan,  
28 Campus Dr., Saskatoon, SK.  
S7N 0X1

***Department Head***

David Mykota  
*Phone:* 966-5258  
*Fax:* 966-7719  
*Email:* david.mykota@usask.ca

***Mailing Address:***

Department of Educational Psychology and Special Education,  
College of Education,  
University of Saskatchewan  
28 Campus Dr., Saskatoon, SK.  
S7N 0X1

## Appendix D: Ethics Approval



**UNIVERSITY OF  
SASKATCHEWAN**

Behavioural Research Ethics Board (Beh-REB)

### ***Certificate of Approval***

PRINCIPAL INVESTIGATOR  
Tim Claypool

DEPARTMENT  
Educational Psychology and Special Education

BEH#  
09-39

INSTITUTION(S) WHERE RESEARCH WILL BE CONDUCTED  
University of Saskatchewan  
Saskatoon SK

STUDENT RESEARCHERS  
Brandan Newton

TITLE  
An Exploratory Study of Formal Support Factors and Quality of Life for Adults with Asperger's Syndrome

ORIGINAL REVIEW DATE  
25-Feb-2009

APPROVAL ON  
07-Apr-2009

APPROVAL OF:  
Ethics Application  
Consent Protocol

EXPIRY DATE:  
06-Apr-2010

Full Board Meeting ☐

Date of Full Board Meeting:

Delegated Review ☒

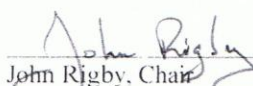
#### **CERTIFICATION**

The University of Saskatchewan Behavioural Research Ethics Board has reviewed the above-named research project. The proposal was found to be acceptable on ethical grounds. The principal investigator has the responsibility for any other administrative or regulatory approvals that may pertain to this research project, and for ensuring that the authorized research is carried out according to the conditions outlined in the original protocol submitted for ethics review. This Certificate of Approval is valid for the above time period provided there is no change in experimental protocol or consent process or documents.

Any significant changes to your proposed method, or your consent and recruitment procedures should be reported to the Chair for Research Ethics Board consideration in advance of its implementation.

#### **ONGOING REVIEW REQUIREMENTS**

In order to receive annual renewal, a status report must be submitted to the REB Chair for Board consideration within one month of the current expiry date each year the study remains open, and upon study completion. Please refer to the following website for further instructions: [http://www.usask.ca/research/ethics\\_review/](http://www.usask.ca/research/ethics_review/)

  
John Rigby, Chair  
University of Saskatchewan  
Behavioural Research Ethics Board

Please send all correspondence to:

Research Ethics Office  
University of Saskatchewan  
Box 5000 RPO University, 1602-110 Gymnasium Place  
Saskatoon SK S7N 4J8

## **Appendix E: Recruitment Email**

The following paragraphs will be included in the recruitment email that will be sent to all members of Asperger's Manitoba Incorporated (AMI):

Dear AMI member,

AMI is conducting research in conjunction with Brendan Newton, a Master's student at the University of Saskatchewan, regarding the current quality of life for adults with Asperger's syndrome who are members of our organization. Although this research is being conducted on behalf of AMI, it is important for you to be aware that it is also being completed as part of the requirements for Brendan Newton's Master's degree. As part of our research project, we are sending this email to every member of our organization to recruit volunteers for participation in this study. If you do choose to volunteer to be part of this study you will be required to click on the link below which will take you to a questionnaire and survey that include questions pertaining to your physical health, psychological health, living conditions, social relationships, involvement in the legal system, education, and substance use. It is estimated that participation in the study will take approximately 15-30 minutes to complete. This study is intended for individuals who have a diagnosis of Asperger's syndrome and are 18 years of age or older. If you do not meet these criteria AMI still welcomes you to click on the link below to answer a few short questions regarding your involvement in our organization. If you decide to participate in this study all information provided by you will be kept confidential and will not be used for any purpose other than the research project indicated.

AMI is hoping that by conducting this research, it will provide us with a better understanding of the current factors that influence quality of life for members of our organization who are adults and have a diagnosis of Asperger's syndrome. Your participation in this research study could potentially lead to increased funding and support from the government of Manitoba, as it is intended that the data collected from this study will be used for advocacy purposes. Upon completion of the study a final report will be posted on the AMI website for the interests of all members of AMI.

It is important to note that participation in this research study is completely voluntary. If you are interested in learning more about this study or are interested in the possibility of a future follow-up interview regarding this study, which may also be used for data collection purposes, please contact Brendan Newton via email at [bjn429@mail.usask.ca](mailto:bjn429@mail.usask.ca).

Thank you.

(Name of AMI board member), AMI

Contact Information:

Brendan Newton, M.Ed. Candidate (Primary Researcher)  
Department of Educational Psychology and Special Education  
College of Education  
University of Saskatchewan  
Email: [bjn429@mail.usask.ca](mailto:bjn429@mail.usask.ca)  
Phone: (306) 966-7720

Tim Claypool, Ph.D. (Research Supervisor)  
Department of Educational Psychology and Special Education  
College of Education  
University of Saskatchewan  
Email: [tim.claypool@usask.ca](mailto:tim.claypool@usask.ca)  
Phone: (306) 966-6931

Ethics Approval BEH# 09-39  
Behavioural Research Ethics Office  
University of Saskatchewan  
(306) 966-2084

## **Appendix F: Electronic Consent Form**

**Research Study Title:** An Exploratory Study of Formal Support Factors and Quality of Life for Adults with Asperger's Syndrome

You have been asked to participate in a research study conducted by Brendan Newton (M.Ed. student) and Dr. Tim Claypool (Thesis Supervisor), from the Department of Educational Psychology at the University of Saskatchewan. The results of this study will be used to complete a Master's degree thesis requirement. This study is also being conducted on behalf of Asperger's Manitoba Incorporated (AMI). Upon completion of the study a final report summarizing the results will be released to AMI and subsequently posted on their website.

If you have any questions or concerns about the research, please feel free to contact Brendan Newton at (306) 343-7499 or Dr. Tim Claypool at (306) 966-6931.

### **Purpose of Study:**

This study is being conducted to gain information on the current quality of life for adults with Asperger's syndrome who are members of AMI. The results will be used to determine whether formal support factors such as transition plans or social skills groups affect quality of life scores.

### **Procedures:**

If you volunteer to participate in this study you will be asked to answer a series of questions pertaining to education, employment, physical health, psychological health, living conditions, social relationships, involvement in the legal system, and substance use. Your participation in this project will take approximately 15-30 minutes.

### **Potential Risks and Discomforts:**

Many of the questions included in the questionnaire and survey are personal. Slight discomfort may be experienced due to the sensitive nature of the topics addressed. If this does occur you are advised to contact AMI who will ensure that your concerns are addressed either through the provisions of relevant information or through referrals to the appropriate professionals or community-based agencies. It is important to note that participation in this study is completely voluntary and participants may withdraw from participation at any time during the completion of the questionnaire or survey.

### **Potential Benefits to Participants:**

AMI intends to use the results of the study to advocate to the government of Manitoba for sufficient funding and support for adults with Asperger's syndrome.

### **Confidentiality:**

Every effort will be made to ensure confidentiality of any identifying information that is obtained in connection with this study. It is not mandatory to include your name or any identifying information in

your responses to the questions on the questionnaire or survey. However, one question at the end of the survey does ask if you are willing to be contacted for a possible follow-up interview. If one does indicate willingness to do so they will be asked to leave their first name only and phone number. However, this information will not be released to anyone other than the primary researcher of the study.

#### **Data Storage:**

The data collected for this study will be stored by the research supervisor, Dr. Tim Claypool, for a minimum of five years. After this five year period the data may be completely destroyed.

#### **Dissemination of Results**

The results of this study will be presented in a report that will be available on the Asperger's Manitoba Incorporated website. The results will also be used for the completion of the thesis component of the primary researcher's Master's degree program and may be presented or published in an academic journal.

#### **Participation and Withdrawal:**

You can choose whether to be in this study or not. If you volunteer to be in this study, you may withdraw at any time without consequences of any kind. You may exercise the option of removing your data from the study. You may also refuse to answer any questions you don't want to answer and still remain in the study. The researcher may withdraw you from this research if circumstances arise that warrant doing so. These circumstances will be completely dependent on whether each participant meets the criteria for inclusion in the study. This study is intended for adults (18 years of age or older) who have a diagnosis of Asperger's syndrome. However, members of AMI who do not have a diagnosis of Asperger's syndrome or who are under the age of 18 are also welcome to contribute to the study by answering a few brief questions.

#### **Rights of Research Participants:**

You may withdraw your consent at any time and discontinue participation without penalty. You are not waiving any legal claims, rights or remedies because of your participation in this research study. This study has been reviewed and received clearance through the University of Saskatchewan Behavioural Research Ethics Board (pending). If you have any questions regarding your rights as a research participant, contact:

Research Ethics Office  
University of Saskatchewan  
Box 5000 RPO University  
Saskatoon, SK Canada S7N 4J8

Telephone: (306) 966-2084  
Fax: (306) 966-2069  
Email: [ethics.office@usask.ca](mailto:ethics.office@usask.ca)

\_\_\_ I am willing to volunteer to participate in this study.

\_\_\_ I am not willing to volunteer to participate in this study.